A STROKE OF BAD LUCK

Reconditioning Mind and Body for a New and Rewarding Lifestyle

by Sebastiaan Bakker
A Stroke of Bad Luck
An Autobiography

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Table of Contents

Acknowledgment — ix
Foreword — xi
How Your World Changes — 1
Getting Out of the Doldrums — 5
My First Steps to Recovery — 11
Find Inner Strength — 17
Under My Own Steam — 25
The Caregiver — 31
Find Satisfaction in Rehabilitation — 37
Look forward and think positive — 38
Balance the use of energy — 38
Communicate — 39
Work for it — 39
Accept compliments for what they are — 40
Train your brain — 40
Keep up your self-esteem — 41
Table of Illustrations

Figure 1 — Total recovery
Figure 2 — Swallowing
Figure 3 — Energy
Figure 4 — Voice
Figure 5 — Quality of vision
Figure 6 — Coordination
Figure 7 — Physical strength
Figure 8 — Balance and walking
Figure 9 — Stress handling
Figure 10 — Multi-tasking
The information found in this book is not intended to be a substitute for professional medical advice. One should not use this information to either diagnose or treat a health-problem and/or disease without first consulting with a qualified health-care provider. Please consult a medical specialist with any questions or concerns you may have regarding your condition. The charts in this book provide an indication of progress of recovery by the author over time. There is no scientific support to the percentages and time-frame. Based on subjective data, they solely illustrate the author’s perception. The curves in the charts will differ for each individual. Despite the lack of scientific value, the author believes that his illustrations and the accompanying text can help others to make their own assessment with respect to recovery.
Acknowledgement

To my wife Dorthe, my two sons, Sven and Henrik, and my family and friends. I owe you my life for all the love, care and patience that I received.

To the professional personnel of Ullevål Universitets Sykehus, Diakonhjemmet Sykehus, Sunnaas Rehabiliterings Sykehus, Cato Senteret, Rikshospitalet, Centrum Logopedi, and my personal trainers.

Finally yet importantly, to all the people who have suffered a brain stroke and their friends and family—that they may benefit from the experience that I have gained and try to share by telling my story.
Foreword

Brain strokes are all different and without discrimination of sex, age, or physical condition. We share one common objective: reconditioning the mind and body for new and rewarding lifestyles, however different that may turn out to be. I hope that I can contribute to a better understanding of what it takes to recover and make it easier for others to draw their own plan or place their situation in perspective.

Like so many things in life, recovery is not something that happens overnight. Unless you believe in miracles, nothing is free in this world. You have to work hard and long to create your own miracles. Accept all the support you can get. Leave no room for negative thoughts. The power of positive thinking is the key to successful rehabilitation. The reward at the end of the adventure of rehabilitation is enormous. The experience made me humble and appreciative of the small things in life. Although uncalled for, that is not a bad thing.
Dorthe and I had celebrated our seventh wedding anniversary with a splendid dinner in downtown Oslo. We had sold our house in the Netherlands a few years earlier. After we had left for Norway, the country where my wife Dorthe came from, we had lived at a number of fine-looking places along the Oslo fjord. Our plans were nearing completion: leaving the short but striking summers and long cold winters behind to live aboard a sailboat in the Mediterranean—at least for a few years until we were ready to settle in a place that we had not yet decided upon. Our talks kept ending on the same topics: the well-being of our two sons—Sven and Henrik—now old enough to look after themselves, and the practical arrangements we would have to make. In anticipation of the change, we had rented a waterfront apartment and further reduced our inventory as we had done during our previous moves.

Drowsily I sat up in my bed; the room was still in total darkness. My sense of orientation had totally vanished. The space I knew so well was gone. Reasoning with myself, I started my
In intensive care, I had told Dorthe not to alarm him unnecessarily. I believed in survival. Instinct knows no rationale. Little do I remember of the days that followed. I lived by the color of emotions: love, trust, and safety. Not until afterward did Dorthe and the boys brief me on the details. For a long time, we did not speak of those dreadful days burdened with fear.

The neurologist’s uncertainty slowly turned into a cautious confidence. After a few days, I was moved to a regular hospital room to begin my healing. My survival seemingly secured; the worst was behind me; yet, I did not know what was coming.

Dorthe communicated every bit of news to the outside world. It was wearing her out physically and mentally, but she saw it as her duty to keep many personally informed. Fortunately, the tam-tam sounded before she buckled under the effort. Dorthe kept Sven and Henrik, my younger brother, and her parents up-to-date. The people she spoke to made sure that the intelligence spread through the family tree. My closest family and friends were there for me. The mental support of their visits was essential, even when I was only half-conscious; my existence was confirmed in the glance at the people I cared for. Their quiet presence mattered.

Maybe I am just being naïve or it may be part of the instinctive survival mechanism, but from day one there has never been any doubt about making it—although Dorthe and I never dared to qualify the state that I could be in long term.

Sven flew in from Amsterdam on the first flight. Henrik arrived immediately after Dorthe had broken the news to him. Our sons were present at the hospital during the first days, and within a matter of weeks, they became frequent flyers. Both of them lived in the Netherlands: Henrik studying in The Hague; Sven, running his own business in the Amsterdam area. I remember that I was afraid to upset Henrik’s studies while he was in the midst of his exams. Already before landing in intensive care, I had told Dorthe not to alarm him unnecessarily. I believed in survival. Instinct knows no rationale. Little do I remember of the days that followed. I lived by the color of emotions: love, trust, and safety. Not until afterward did Dorthe and the boys brief me on the details. For a long time, we did not speak of those dreadful days burdened with fear.

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Maybe I am just being naïve or it may be part of the instinctive survival mechanism, but from day one there has never been any doubt about making it—although Dorthe and I never dared to qualify the state that I could be in long term. We did not discuss that topic until the “medical emergencies” showed signs of recovery. Both of us silently decided that we would live with the limitations that could not be restored; as inconveniences, we banned them from our thoughts. What we had done was to separate the important functions that
Shoots can grow to become big trees, but once a plant, always a plant. I have never been that plant—neither in intensive care nor at any other time on my sickbed, however slow my mind or fragile my life might have been. I resent the qualification; it is negative, inaccurate, and holds nothing for the future. I am human and have a brain. I have intellect, emotions, memories, and willpower.

In casual conversations, it was easy for people to describe my condition after the stroke as a “vegetable” when trying to make their point. I know it is nothing more than an innocent cliché, but the analogy mattered to me. In my presence, people knew not to use the expression. I had survived, and I was determined to get my life back. I was not going to end up on the windowsill to be watered, if not forgotten, or talked-down to. For the rest of my life, I could be in need of permanent nursing. That worrisome outlook was dismissed from day one; my focus was on reconditioning mind and body for a new and rewarding lifestyle. It was an open-ended endeavor. I was determined not to give in without a fight. My battle
strategy was based on trust, perseverance, and patience. Like a newborn, I relearned the most basic skills.

Calling a brain stroke a “valuable experience” is nonsense. It is just another cliché. Life does not come without thorns. Yes, I learned a lot, but I never asked for the insights, and it has cost me my dreams. I was happy with my life as it was. With the experience, not my values but my attitudes have changed. I have become milder, more subtle in ventilating my opinions, and an empathic listener, but I became less forgiving to negativism that undermined my goals. I could hardly control my emotions when a fellow patient kept complaining about his misfortune: “I used to run up and down the stairs. I can’t do that anymore.” His nagging was poison to my motivation. What mattered was today and, the future, not the past. What I could or could not do was water under the bridge. I was grateful to be alive.

The reasons for my early retirement had been diverse; many of my generation had passed away, which made me fear for my health, and I wanted more out of life than work; I wanted things that would be difficult to realize as a pensioner. Getting a stroke was pure irony, a stroke of bad luck.

I submit myself to the unruffled beauty outdoors: white and frosty during the Norwegian winter, the sky full of stars, continuous daylight during the summer, and the warmth of Spain. I appreciate things in life more than before. None is materialistic: a short ferry crossing over the Oslo fjord, exuberant autumn colors, or watching the flow of people from a terrace at the port. A greater consciousness has taken over. There is no reason to feel sorry for myself.

I look out over Vigeland Park from behind a small desk on the veranda and observe, reflect, and think; I meditate.
individual, which in turn is the sum of attitude and one’s search for happiness. For starters, try living a life that gives personal satisfaction through doing the right things the right way. It may be in your own privacy or publicly, in your hobby, the arts, science, or community. A rewarding life often starts with sharing your talents, skills, or knowledge. Consistently making small contributions will add up to something to be recognized for. I went back to basics and shared the things I did best and people acknowledged me for it. Despite my limitations, I could add value to the lives of people around me.

My relationship to others has a big impact on the way I experience quality of life. I realized that when the ones I loved visited me in the hospital and reflected on our memories. I enjoyed it then and even more so now. Investing more of my time in personal and professional relationships has strengthened my sense of living a rewarding life.

Happiness is an agreeable feeling of well-being which assumes being at peace with yourself. People are all unique, and what is valid for one does not have to be true for somebody else. Even so, there are a number of common denominators in reaching a state of happiness.

Happiness is driven by positive emotions that relate to what lies ahead of us, behind us, or in the present. Optimism, hope, and trust are emotions of the future. Satisfaction, pride, contentment, and inner peace are positive emotions from the past. The longer the list of positive experiences, the more valuable the memory; it adds stability to sentiment. That is not necessarily true for the short flashes of superficial pleasure in daily life; it is easy come, easy go. Overeagerly chasing stimuli, without having confidence in the future, is not enough to produce a long-lasting feel of happiness. On the other hand, when devoting yourself to others consistently, it will create a sustainable feel of happiness.

Like attitude, my search for happiness implied making choices. The stroke had drastically changed the circumstances, which called for a new look at the way I would live my life. The obvious step to take was to radically dismiss all negative forces and to avoid situations that I could not step up to. It meant detaching myself from negative sentiments such as pessimism, discontent, and shame that could undermine my feelings of well-being. I could not let them influence my reactions or recovery. Conversely, I used my energy on optimism, gratification, and pride. I claimed the freedom to positively discriminate people and set my own itinerary. The approach narrowed but deepened my social life. Now, I could give undivided attention to the people who mattered. Secondly, I will always be grateful, not for the stroke, but for what I am today and for the people who love and care for me. I know no bitterness. There is no blame, just gratitude and the power of pride. Last, but not least, I took control over my future. Now, a few years after the stroke, I am still busy recovering, or better said, relearning.

Dorthe is back to work in the fashion business. Now it is my turn to be the caregiver. Solidarity starts early in the morning with making a pot of fresh coffee. During the day, I putter around, attend to domestic and social chores, do the shopping, and write. The old Jag is parked in the garage; I am hardly behind the wheel. The driver’s seat is Dorthe’s post; polishing is my meditative work: wax on, wax off. We exclusively travel by car for our joy and the journeys are as pleasurable as the destinations. The trips through continental Europe and Scandinavia gave us inspiration, quality time, and privacy.
Appendix 1 – Personal Economy

Sudden hospitalization and a long recovery process can have a big impact on the personal economy and domestic administration, particularly if the patient runs his or her own company or is self-employed. It may be necessary to transfer the day-to-day management to a business partner or a well-trusted employee or to hire an interim manager to ensure continuity. Without insurances, it may be difficult to maintain income or continue the business. How to act in a worst-case scenario is best considered before things go sour, but most people put off such an unpleasant task until it is too late. It could then be up to the caregiver to make the best out of it. Delegate specialist tasks; for one, because there might be little time left to attend to them properly. The tasks of a caregiver are already demanding enough without the extra workload and added stress. Technically, physically, or psychologically, it may be too much to handle.

Not all tasks related to the economy at home have to be that complex. When employed by a larger corporation, it tends to be a bit easier. Open communication with the
A Stroke Of Bad Luck

Statistics for a brain stroke make horrifying reading. It is not something people like to look into unless confronted with the situation; neither did I. In a way, my wife and I are glad not to have fully understood how serious the circumstance of the hospitalization was. I now realize how lucky I am to be what and where I am today. A word of comfort: statistics are anonymous, and there is only one of you. With conviction, hard work, and a bit of luck, it is possible to beat the average.

The scary news is that brain strokes are the number one cause of adult disability and the second leading cause of death worldwide and third in the US. The other infamous top two are heart disease and cancer. A change in lifestyle

Appendix 2 – Statistics

Statistics¹ for a brain stroke make horrifying reading. It is not something people like to look into unless confronted with the situation; neither did I. In a way, my wife and I are glad not to have fully understood how serious the circumstance of the hospitalization was. I now realize how lucky I am to be what and where I am today. A word of comfort: statistics are anonymous, and there is only one of you. With conviction, hard work, and a bit of luck, it is possible to beat the average.

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¹ Source compilation (2007-2009): American Heart Association (AHA), American Stroke Association (a division of the AHA), American Society of Interventional and Therapeutic Neuroradiology, American Brain Attack Coalition, Centers for Disease Control, The University Hospital New Jersey, National Institute of Neurological Disorders and Stroke (NINDS), National Stroke Association, Centre for Chronic Disease Prevention and Control, Canadian Cardiovascular Society, Heart and Stroke Foundation of Canada, World Health Organization.
Europe averages approximately 650,000 stroke deaths each year. In developed countries, the incidence of stroke is declining. This is largely due to efforts to lower blood pressure and a reduction of smoking. However, the overall rate of stroke remains high due to the aging of the population.

The estimate of the economic cost of stroke in the United States is a staggering forty-three billion USD annually. Of this amount, nearly two-thirds is for medical care and therapy. The indirect costs from a loss of productivity and other factors cover the remainder. The average cost of care for a patient up to three months after stroke is fifteen thousand USD. For ten percent of the patients, the cost of care for that period is more than double that. The direct costs of care for the first months is broken down to initial hospitalization (forty-three percent), rehabilitation (sixteen percent), physician costs (fourteen percent), hospital readmission (fourteen percent), and medications and other expenses (thirteen percent).

A Stroke Of Bad Luck

after a stroke can make a big difference for one’s future when considering the outlook of a recurring stroke. A quarter of the victims have another stroke within the first five years.

The numbers paint a nasty picture. According to the World Health Organization, fifteen million people suffer from a stroke worldwide each year. The impact on human life is enormous: a third recover, a third are permanently disabled, and a third die.

Brain strokes affect more than seven hundred thousand individuals annually in the United States. Well over half a million of these are first attacks; the remainder are recurrent. More than four million people in the United States have survived a brain stroke and are living with the after-effects. Somehow, brain strokes affect four out of five families over the course of a lifetime. According to the American Heart Association (AHA), someone suffers a stroke every forty-five seconds.

The incidence rate for a stroke of bad luck varies by gender, race, and age. Occurrences lie between fifty-nine to ninety-three victims per one hundred thousand people. Statistically, male African-Americans are the worst off. Numbers from the United States indicate that more than a third of stroke victims recover almost completely or sustain only minor deficiencies. Forty percent experience moderate to severe impairments. Ten percent will need permanent care in a nursing home. Fifteen percent do not make it. Bleeding into the brain due to a rupture of one of its blood vessels causes the so-called hemorrhagic stroke. It is the most severe. Although it accounts for only seven percent of all strokes, the fatality rate is over fifty percent. Of the survivors, approximately half suffer permanent disability.
Appendix 3 - Timeline of Recovery

Month, location, and primary activity:

0–1  Ullevål Universitet Sykehus, Oslo, Norway.
     Intensive care and medical emergencies.

2–4  Diakonhjemmet Sykehus, Oslo, Norway.
     Medical treatment with the focus on nutrition and initial rehabilitation.

5–7  Sunnaas Rehabiliterings Sykehus, Nessodden, Norway.
     Dedicated first line rehabilitation.

8–9  Cato Rehabiliterings Senteret, Son, Norway.
     Dedicated second line rehabilitation.

10–17 At home. Oslo, Norway.
Vocal cord operation. Private rehabilitation. Voice therapy and personal training at SATS Fitness Centre. Mostly indoors.

18-33 Temporary move to Puerto Banus, Spain.

Private rehabilitation. Physical training at the Platinum Wellness and Fitness Centre. Mostly outdoors.

34-36 At home. Oslo, Norway.

Private rehabilitation. Physical training at Elixia Fitness Centre combined with outdoor activities. Return to society.

About the Author

Sebastiaan Bakker was born in Amsterdam, the Netherlands in 1951.

Educated as an engineer, he worked most of his professional life in a variety of executive management positions for an American Multinational in the IT sector until his early retirement in 2001. He prepared for living aboard a sailboat in the Mediterranean with his wife until he suffered a stroke in his brain stem, which wiped out nearly all of his physical and biological stability and life support systems.

Ironically, his decision for retirement was strongly related to the loss of his first wife to cancer and many colleagues and friends who died young or shortly after having reached their pension age. Now his world was once again turned upside down. In his book, he describes what it takes to come from a position where breathing was the only thing he was capable of, to his happiness three years later.
His focus is on the power of positive thinking in the rehabilitation process. The problem, other than understanding it, is not worth his energy; only the solution matters. From one day to another, he ventured into a new world where nothing could be taken for granted and all his functions required reprogramming. He found himself in a new job, one in which he would need all his professional experience mixed with optimism, motivation, a strong discipline, and self-management skills. Failure was no option.

Practical examples give a unique insight, from medical recovery to the return to society, to patients as well as family and friends. Many readers can gain from the understanding that arises. Illustrations show the process of healing over time by key area: medical, mental, and physical. He found a new and rewarding lifestyle by overcoming the challenges of everyday life: step-by-step, day in, day out.

Embedded in his personal account are numerous hints and tips and points to consider. Rather than plain telling, the story triggers the imagination and makes it easier to recognize behavioral or physical symptoms. By doing so, the author hopes to reduce the struggle by other individuals who ended up in a similar situation and of those in their surroundings. The importance of the role of caregiver is intertwined with the story throughout the book and summarized in a dedicated chapter.