

Chris Maxwell has a story everyone needs to hear. His once ravaging brain infection and his successful life with permanent brain insult defy simple explanation.

My perspective of Chris Maxwell has evolved from that of a casual acquaintance in our youth to a valued personal friend with whom I share a weekly morning breakfast and intimate life conversations. In Chris' youth, long before his illness shattered life as he knew it, Chris was the epitome of a flamboyant extrovert with a dynamic personality and unbridled energy. Chris now leads a very busy life of counseling, speaking engagements, travel, teaching, and authoring numerous books. He does so in a quite measured, incremental, intentional, and methodical manner. His mastery of technology and adaptation to somewhat rigid, self-enforced personal habits and schedules contribute to his success. His management of his residual brain disorders and their daily challenges go unnoticed by most folks. If Chris didn't share his story, I'm certain most people would be unaware of the "valley of death" which once threatened to destroy his brain and swallow his life, and they would also be in awe of the height of the mountaintops he subsequently climbed!

As a physician, I understand the medical ramifications of Chris Maxwell's near-death brain infection and its resulting brain insult. As his friend, it is remarkable to witness Chris' ability to turn his nightmarish medical crisis and disability into a source of inspiration, encouragement, and hope for others. He endeavors to tell his story for the benefit of humanity.

Chris Maxwell's story brings new dimension, deeper insight, and refreshing perspective. I am pleased he has chosen to share it!

— James R. Swails, M.D.

I was hired on pastoral staff after Chris had returned to work. I never knew Chris before his illness but realized quickly that he had become a new man. People would recount stories of the former Chris with great pride and a sense of community. Even with the difficulties of names, recollection of facts and dates, and the visual discomfort it caused Chris, people continued to crave his investment in their lives. He was still their pastor.

Chris mourned his prior self, was frustrated at his limitations, longed to work all day without naps, and wept at the pain that his family had suffered. Yet in all of this, I witnessed a man who grew and accomplished greatness. Chris worked extremely hard to overcome and would constantly strive to improve. There were many days when Chris pushed too hard and would have to stop and regroup. These setbacks would become fuel to move forward. Chris would comment daily on his small victories in the overwhelming flood of God's Grace.

Throughout this crippling journey of recovery, Chris became a new man. He found his purpose and voice—not as a victim, but as a survivor and overcomer. The man I know puts people before programs, forgiveness before frustration, healing before hate, and joy before mourning. Chris will be the first to recognize that he is a miracle.

– Dr. Edward Clack D.O

I met Chris Maxwell by “pre-ordained accident.” He reached out to me as someone suffering from epilepsy while I was working to change, thinking about this dreadful disease. I didn’t know his name on my phone message list, so it languished there for several weeks. When we finally communicated, my life changed. And so did thousands of others. I had a platform with not much to put on it. Chris had a message. Don’t give up. Don’t give in. Don’t doubt yourself. You can make a difference.

I watched him deliver this message in many states in the United States, in Tokyo, Japan, and in South Korea. I watched people of different cultures, experiences, and stages of life all nod in agreement when Chris talked about change and hope and progress. I watched believers and non-believers see a Christlike spirit of love, kindness, and grace encourage them. I witnessed Chris change the lives of hundreds of people across the years . . . just because he had the courage to encourage.

Chris’ only tool in this journey was words—words that put just a little piece of himself into their hearts. The piece of himself that said, “It’s okay . . . it’s all going to be okay.” His writing is an extension of Chris, and it will put a little piece of him into your heart as well. Just as I have learned to drink in every minute I get to share with Chris, I encourage you to drink in his words. Just like me, your life will be changed.

– Tom Roberts, Managing Director, UCB

Coming from a near-death, life-threatening medical condition, Chris Maxwell knows firsthand what it is like to feel “underwater,” fighting for life. His story is a modern medical wonder and is bringing dignity and hope to people around the world. His voice is being heard at medical conventions, university campuses, and in places of worship. I heartily endorse him and encourage you to have him speak to your organization.

– Dr. A.D. Beacham, Jr., General Superintendent
International Pentecostal Holiness Church

I met Chris Maxwell on the campus of Emmanuel College almost eleven years ago. In our very first conversation, we both knew we had found a friend and even joked about how awesome it would be if we were ever given the opportunity to work together. Be careful what you ask for! We just completed our tenth year working together on the same campus. I never knew the “old” Chris Maxwell, but I read his books, studied his life, and have gotten to know the current Chris extremely well. For many years, we have met weekly to talk, listen, laugh, cry, think out loud, dream, and learn together. We text each other at all hours of the day and night. He can complete my thoughts and finish my sentences. I know his routines, habits, daily rituals, what foods he likes, where he likes to eat, and, often, what he is thinking or feeling. We look out for each other and lean on each other for strength. He is a gift to my life, and I sincerely hope I am a blessing to him as well.

My Chris Maxwell uses words and images to shed light and create life. He thinks, he prays, he writes, and he speaks. His words are well-chosen because they are precious to him. He invests them into our lives strategically in hopes of bringing hope, commonality, mutuality, and trust for a brighter day and better tomorrow. But don't just read the words. Feel the pulse of life, sense the joy in the journey, and embrace the hand of a friend who understands pain, disappointment, temporary setbacks, challenges, hard work, and the routine of daily repetition. Walk with him as he does the sacrificial work of reliving the nightmares of the past as a means of birthing new life and vision for a brighter future for your life. Savor every second and live every moment as if it were all you have. Dive in. Take the plunge. Go deep. Emerge as a better version of you. It can be done. You can learn to live again.

– C. Tracy Reynolds, VP for Student Development
Dean, School of Christian Ministries, Emmanuel College

I remember the day in March 1996 when we received a phone call that our friend and pastor Chris Maxwell was in the hospital, and they weren't sure exactly what was wrong. We came to learn that he was diagnosed with encephalitis which is swelling in the brain. This educated, articulate, and compassionate man had to relearn how to hold a spoon, use the bathroom, and his family's names. All of a sudden, Chris was not the man we knew before. Little did we know the intricate plan God had before him or the people he would meet and touch along the way.

As Chris struggled to learn things all over again, he faced frustrations but also experienced miracles! His healing and accomplishments far exceeded what anyone thought possible! People he might not have ever met if it weren't for his illness were touched by his authenticity and his raw love for God.

The struggles brought Chris further in his faith in a new and fresh way that he may not have reached had he not gone through those physical and mental difficulties.

Today, Chris is educating and inspiring others who have epilepsy. A beautiful picture of how God turns what appears to be a tragedy into blessing, growth, and inspiration for others!

– Marsha Bozeman, Family Nurse Practitioner

I had the pleasure of meeting Chris several years ago when he and I were scheduled to speak at the same program. He is an outstanding speaker! His was a hard act to follow. His talk was extremely well-delivered, inspirational with just the right touch of humor. You find yourself wanting more when the talk ends.

I am equally impressed with Chris' writing ability. It is the kind of writing that makes you think, "I wish I could write like that." He wrote an essay on New Year's Day that I have forwarded to folks all over the country and a few out of the country.

I have seen how Chris relates to people in the audience, the folks who come up to talk to him afterward, and how he seems to instinctively know what they are asking that is not spoken. He is a hero and one the world badly needs. How lucky are those college students who have access to him. What a role model to have at this time in the world.

– Patricia A. Gibson, MSSW ACSW, Associate Professor
Wake Forest University Health Sciences

It was an early morning breakfast appointment. I arrived on time, and my friend who I was going to meet was always early. To my surprise, I beat him to the restaurant. That never happened, but that day it did. I waited on his arrival. My friend and pastor was Chris Maxwell; he never showed. I called and found out later that he was in the hospital with encephalitis. This mysterious disease almost took the life of my friend, but God was gracious. Today, my friend's mind and memory have limitations that did not exist before that day, but his heart has been enlarged, and his sensitivity toward God and others is without measure.

– Tim Kuck, Executive Vice President and C.O.O., Regal Boats

When Chris suffered a debilitating attack of viral encephalitis, he had been my friend, youth pastor, and then pastor for over ten years. I'd met him shortly after moving to the Orlando area when I attended a youth service he

was leading. I liked him. Chris was an intellectual and a poet (and still is), and most of all, people were drawn to him and then, through him, to Christ. He was a young, charismatic pastor who used mnemonic devices to memorize the names of every parishioner, spouse, and their children in every congregation with which he associated, and his number one message—a message that he reinforced with his own deacon board and church later on—was the message of God’s unconditional love and acceptance. Because of his commitment to that message, I witnessed many broken people over the years receive healing under his ministry, and I saw unconditional commitment extended to so many of us despite our failures and sin. It was unsurprising, then, that when his illness took away his ability to speak coherently that his congregation unconditionally rallied behind him. There wasn’t any talk about replacing our pastor even though the prognosis was bleak. And six weeks later, miraculously, he was back in the pulpit. He struggled, but his message was clear. And years later—many years later—he is still writing, speaking, and preaching. I have no doubt that he carries the burden of his illness every day, as does his wife Debbie and his children, but he is now, more than ever, like the high priest of Hebrews who is not unfamiliar with our sufferings. When he writes about faith, suffering, and perseverance, it is because of his own intimate struggle with all three. What you are reading in his words aren’t platitudes, but blood and bone and flesh and suffering and the ways that God’s love comes to us through all of these.

– Dr. James Rovira, Chair and Associate Professor of English
Mississippi College

Chris Maxwell is a dynamic leader with a message of inspiration. He motivates the masses to live beyond the diagnosis of encephalitis and epilepsy to find their true purpose and calling in life, not by asking “why,” but by encouraging others to find their stories of strength. His unique speaking and storytelling is in a league of its own, comprised with compassion and thoughtfulness. Chris invites you into his journey with a tranquil voice and captures your attention with optimistic words that speak to the core of your being. For my personal experience of living with epilepsy, his speaking, writing and stories are the epitome of hope.

– LaKeisha Parnell, Confidence Coach, International Speaker, Author,
Founder of LPForward, LLC

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UNDER WATER

When ...

- ENCEPHALITIS,
- BRAIN INJURY and
- EPILEPSY

... Change Everything

CHRIS MAXWELL



True Potential
REACH THE WORLD

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Most of the names and stories included are accurate. A few names have been changed or are not included, and a few stories have been slightly altered to protect the privacy of those providing their stories.

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Appreciation and Dedication

As for me, I need to tell a story.¹ —Kathleen Norris

Thank you to my family and friends, my doctors and caregivers, my counselors and accountability partners, my readers and students, my editors and publisher. Life in the plural helps all people—especially those of us who frequently feel singular and lost at sea. This book hopes to honor and encourage all those who have some type of brain damage and often feel that way—*Underwater*. Though memory is difficult for many of us, let's remember we are not alone. Let's remember we are loved. And let's encourage one another to find joy underwater as we endure the adventure.

1 Kathleen Norris, *Acedia & me: A Marriage, Monks, and a Writer's Life* (New York: Riverhead Books, 2010) 47.

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Foreword

By Dr. Hal Pineless

I met Chris Maxwell on a Friday afternoon. I was the neurologist at the hospital, and I was finishing hospital rounds when Dr. Adler, the hospital infectious disease specialist, asked me to see Chris. Chris was confused and had a high fever. He spoke nonsensically; had impaired comprehension, and naming. His wife and family couldn't believe the sudden change in Chris' personality.

Chris was a successful Orlando pastor beloved by those whose lives he touched. Chris could remember the name of everyone he met prior to his illness. That changed after Chris was diagnosed with herpes simplex encephalitis. His MRI of the brain looked like Swiss cheese, and I knew it was permanently scarred. Chris was rapidly treated with medications as, luckily, herpes encephalitis was treatable with medicine. Chris developed seizures as a result of his encephalitis, which isn't uncommon. His seizures eventually became controlled with medication.

After hospital discharge, Chris needed extensive rehabilitation. One of Chris' biggest problems was learning to speak, name, and comprehend. The encephalitis destroyed his left temporal lobe, which is important in such functions as memory, naming, expressing emotions, hearing, and auditory processing. Seizures commonly develop in the temporal lobe as well.

Thankfully, Chris was innately stubborn, and this served him well during his rehabilitation. He gradually regained the ability to speak and comprehend. His language skills improved exponentially—nothing short of a miracle.

Now Chris is a prolific author, pastor, radio commentator, and lecturer. He has truly taken a lemon and made it into lemonade. Chris has become a passionate epilepsy advocate, and speaks internationally about his experiences overcoming his illness and epilepsy.

If any neurologist looks at Chris' MRI of the brain and then sees Chris, they can't believe they are looking at the same person. Chris could easily have gone into a deep depression over his illness. His tenacity to stubbornly refuse to lose is what made him into the winner in life that he is today.

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I hope that when you read *Underwater: When Encephalitis, Brain Injury and Epilepsy Change Everything*, you will realize that, like Chris, you too have the ability to dominate over your obstacles. Don't let epilepsy or your illness define you. You can succeed in life if you believe in what you are doing and are willing to fight for it. I hope that you will like this book and that it will help you in your journey through life.

Hal S. Pineless, D.O., FACN

President, NeuroCare Institute of Central Florida, Winter Park, FL

Clinical Assistant Professor of Medicine (Neurology)

Florida State University College of Medicine

Medical Director, NeuLife Rehabilitation, Mt. Dora, FL

Introduction: The Song

I had passed from the subject to the direct object of every sentence in my life.¹ —Paul Kalanithi

I have been feeling very clearheaded lately and what I want to write about today is the sea. It contains so many colors. Silver at dawn, green at noon, dark blue in the evening. Sometimes it looks almost red. Or it will turn the color of old coins. Right now, the shadows of clouds are dragging across it, and patches of sunlight are touching down everywhere. White strings of gulls drag over it like beads.

It is my favorite thing, I think, that I have ever seen. Sometimes I catch myself staring at it and forget my duties. It seems big enough to contain everything anyone could ever feel.² —Anthony Doerr

I don't know much about life underwater.

But I remember experiences as I glance back in time.

Learning to swim as a kid while Mama watched, smiling. Those fun moments of riding the waves in brief visits to the beach as a child, then as my wife, Debbie, and I were raising our sons. Catching a bonnethead shark by hand—twice—on a vacation with the family. Riding with a dolphin at a theme park. Going on a cruise, visiting the islands of Bequie, Dominica, St. Martens, St. Lucia, and other spots as we noticed beauty at sea and on shore. Snorkeling with Debbie on our trip to Cancun.

The underwater endeavors lure me. The researchers impress me. Their knowledge and experience invite me to investigate. I've dreamed about lengthy periods of time underwater—staring at the gorgeous colors, swimming among the dazzling creatures, slowly adjusting to a new reality.

1 Paul Kalanithi, *When Breath Becomes Air* (New York: Random House, 2016) 141.

2 Anthony Doerr, *All the Light We Cannot See: A Novel* (New York: Scribner, 2014) 405.

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I've also feared the unknown and the unsafe. I've wondered if I entered the water, would I ever be able to find the boat and come ashore.

But figuratively—and in the context of this book—I actually know much about living underwater. As I wrote in *Changing My Mind*,³ I know much about remembering less. I know much about being tossed deep below the surface—no advance warning, no prep work, no guidebook, no six weeks of training.

I fell, or rather, was thrown into the ocean. Wearing dress clothes, carrying the luggage of a normal life in our preplanned world, smiling at faces of friends staring back, assuming all was under my own control, I slipped from the safety of a normal life and landed deep in the water.

Would I survive this calamity?

What would life be like before returning to land?

If I did emerge, how different would I then be?

That story and those questions are not about a real ocean. My sea encounter was about my life and my brain and about the lives of those around me changing suddenly through an illness I barely survived.

The underwater image comes from a song Taylor Maxwell, our oldest of three sons, wrote about how he felt as a young man watching his father change.

The word *Underwater* became the title of his song. And since the mood fits where we travel in this book, he gave us permission to use that same title.

How Taylor felt writing the song is a good place for us to begin this journey.

Why did he write the song “Underwater”? “I just wanted to process the emotions of growing up with a dad that had some brain disabilities.”

What about your father's illness caused you to feel that way? “It all felt pretty unfair to me. Other than the fact it didn't take his life, I just couldn't understand why so much could be taken from such a good guy. Really, from all of us. The way we all had to do life after he became ill felt so unnatural to me.”

When Taylor wrote, “I've been living underwater, on my own and all the time,” he “felt in no man's land. The point I was at—growing up as a young man, making my way through high school. It felt lonely.”

The song is sad but ends well. How can life stories like ours and those of many others with brain damage end well?

3 *Changing My Mind* is Chris' first book that chronicled his recovery from encephalitis.

Introduction: The Song

Taylor says,

It takes adjusting. I think, especially nowadays, there's this unrealistic drive to reach back in time to the "good ole days," when really the best days can be up ahead. Living in the past is what kills the present. Embracing the present is what shapes the future in new and exciting ways. Life will never be like it was—for anyone. But the amazing thing about life is that we can always be diligent to work towards a more hopeful tomorrow when we breathe deeply in each moment.

Because he is my son, he knows me well. How would he describe ways his dad still feels underwater, two decades after the illness first hit?

I don't really know, other than how unnatural it is for someone to experience what he did. It's unnatural to be underwater. But once you learn there is a lot to explore there—you can open up new and exciting possibilities. I think he's in that phase. By embracing the incredible challenge, and yet, still moving forward in hopeful exploration.

What can other people do to come up from living underwater?

There's a work being done in us all underwater. So really, the way I felt writing the song or going through challenging points in life is that you only resurface when the deep underwater work is done.

How can this new book help patients and their caregivers realize they feel underwater while also encouraging them to come up for air and swim onto land?

It's okay to have an honest assessment of what you're dealing with. Sometimes it takes us identifying others who are in the same situation as we are and being honest with each other. There is a coming ashore moment when you honestly embrace the new you.

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What can this book do to help others take those steps to recovery?

Stay in the moment. Let the present struggle do its good work in you.

Yes, it felt strange interviewing my own son about my life, about his life, about our lives, about the life underwater of so many people. But even through the terror underwater, we've remembered to love. We've chosen to endure. And we have helped each other in the process.

Another person remembers the old me and the new me, the pre-illness Chris and the post-illness Chris. I served as Mary DeMent's pastor as my life almost ended—as the life I had known did end. Her comments come from her lenses as a counselor and a friend:

To me, Chris is more than fine considering what he has been through. I tell my friends that they would not notice any difference. And it's true. Those who don't have regular contact with Chris would probably not detect any changes in his behavior, his sermon delivery, etc.

Sometimes, though, I notice subtle changes. For instance, Sunday. He struggled reading a certain word during his sermon. The word was posted on an overhead PowerPoint presentation. Something he never used. He held sermon notes. Something he never did. He wiped his mouth repeatedly. Like a nervous habit. Something he never had.

He struggles to remember names, not faces. Addresses, not places. Most middle-aged people can relate. But not Chris. He never, ever, struggled in that way. He would deliver his entire sermon, including lengthy portions of Scripture, note-free.

I often wonder the toll his memory loss has had on him. When someone we know dies, we grieve. We cry, doubt, bargain, and later accept. Surely, he must grieve the loss of the skills he once possessed.

I wonder what stage of grief he is going through, or does he go in and out? It must be difficult. Sometimes he talks about it; most times, from my vantage point, he keeps the pain to himself.

Introduction: The Song

In *Underwater*, some of the grief will come out. Some of the pain will be released.

Please join me on the voyage into my own Neverland, my own Narnia, my own life underwater. Find yourself and your own story within my story and the stories of others. Be honest about yourself. Know yourself well.

And listen.

Listen to deep hurts and large hopes. Listen to reluctance, but dive in anyway. Listen to voices condemning you, and silence them. Listen to voices encouraging you, and receive them.

And listen for a song. A new version of an old song. A song about you—your past and your future, your pain and your pleasure, your wounds and your healing, your limps and your blessings. Listen to it. Learn it. Sing it.

While staring at the gorgeous colors, swimming among the dazzling creatures, and slowly adjusting to a new reality, embrace the wonder underwater.

SAMPLE

Surprises

Encephalitis is a thief. . . . [It] has quietly been at work for hundreds of years, robbing families of their loved ones, and even in those families where the person survives, it robs them of the person they once knew. Encephalitis steals survivors' capacity to remember as well as their personalities and the types of abilities we generally take for granted: memory, concentration, attention, thinking, judgment, inhibition. For many, there are additional outcomes such as epilepsy and levels of fatigue so great that returning to work or education will remain elusive. This is, of course, where the person survives; many don't.⁴ —Ava Easton

The human brain is the most complex of organs—an intricate network of some 200 billion nerve cells and a trillion supporting cells. The brain controls all bodily activity, from heart rate and movement to emotion and learning.⁵ —Diane Roberts Stoler, EdD

Goodbyes can be painful.

We shook hands. We hugged. We laughed. We promised to continue dialogue.

I was waving goodbye to family. Not a biological family. Friends I've known for a decade. Fellow partners in this adventure this book calls "underwater."

4 Ava Easton, *Life After Encephalitis: A Narrative Approach* (New York: Routledge, 2016) 4.

5 Diane Roberts Stoler and Barbara Albers Hill, *Coping With Mild Traumatic Brain Injury* (New York: Avery, 1998, 7.

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Together we've told stories and enjoyed meals and shed tears. Our adventures of life with epilepsy have felt like swimming through oceans of deep water, fierce currents, and unknown surroundings. I'll tell a few of their stories in this book.

I was excited about my plans for the evening, but on that afternoon, I was ready for a nap. Though exhausted from a few days of learning more about epilepsy and spending time with that family, the goodbyes felt like those who fully understood me were leaving. Part of the need for a nap was my brain's yearning to recover from its ongoing endeavor of overwork. Part of the need was a feeling of grief.

Did You Know?

Epilepsy affects over 3 million Americans of all ages—more than multiple sclerosis, cerebral palsy, muscular dystrophy, and Parkinson's disease combined.

source: cureepilepsy.org/aboutepilepsy/facts.asp

Healthy grief. A realization that grieving well is good. When saying goodbye, when departing from those who fully understand you, when swimming from the underwater life you've become familiar with to the life ashore that others find fun, a type of grief is good.

I skipped the hotel elevator and chose the steps. I smiled with appreciation. I shed a few brief tears not knowing when I would see those friends again and remembering those whose health problems have ended their lives.

I took a nap.

When I woke up, I was thinking about this book and those friends. I was waiting for my wife, Debbie, to arrive. I was reaching for the computer to write and thought of these words: *We never said goodbye.*

At first, I tried to think which friend with epilepsy I missed telling goodbye. As I often do, I struggled to remember.

Then I realized the thought wasn't about that weekend or those friends. It was about my adventure underwater. It was about the abrupt invasion of an illness into my life, into the life of my family and friends. It was about what happened in March 1996. It was about the man that I was and the man that I am—two very different guys in so many ways.

We never said goodbye to that me.

Surprises

I wanted to talk to him—the former Chris.

I would be surprising Debbie later that day as I took her to a nice restaurant by the water in Atlanta, and I thought, *Wouldn't it be nice for her to see again that former me, that pre-illness me, that me she met, that me she married, that me she lost? She never said goodbye to him.*

Would she enjoy dinner better with that me instead of this me?

But she can't. She will arrive and have dinner with me, a man with epilepsy.

Do you know about that word? Do you know about how many of us with epilepsy feel underwater?

Epilepsy is derived from a Greek word, meaning “to possess, seize, or hold.” That meaning isn't Greek to the three million Americans experiencing epilepsy. Most feel possessed, seized, or held back. As I battle with epilepsy, I play with the word instead of letting it play with me. Can't those of us with epilepsy choose to possess, seize, and hold our days? Sure we can—because there's hope. For me, hope means that there are effective treatments and ways you can control your epilepsy and live your life.

But too many people who face epilepsy are trying to endure their experience without hope. They feel alone and isolated. They don't understand their medical options and they struggle to seek the best care that is available. While governments and cultures argue various opinions about health care, individuals and families are concerned about seizures, about side-effects of medications, about driving a car, about getting enough sleep, about life.

And the numbers of people living with epilepsy and brain damage continue rising.

Think. Fifteen seconds. They race as you read these words. During that quick moment, one person in America sustained a traumatic brain injury.

Total numbers? Over 1.5 million Americans sustain a traumatic brain injury each year. And 80,000 of us experience onset of long-term disability following those injuries. These statistics reveal a large, confused, sad audience.

For that audience, we offer *Underwater*. We offer narratives and ideas. We use authenticity to pursue community. We might have more questions than advice, but we want readers to say goodbye to the silence about epilepsy. We want readers to say hello to an honest discussion about the adventure underwater—the condition and what all it brings. And we want readers to find—amid the stories of pain and uncertainty and seizures and medications

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and side-effects and naps and needing help from friends—hope. A positive perspective no matter what else we face. A sense that good days await. A certainty that we aren't alone.

As you read, notice your own life. Through my story and the stories of others, think about your story. Begin believing like never before that the next chapter of your story will bring a few smiles. Believe those smiles can begin now.

- Epilepsy affects over 3 million Americans of all ages—more than multiple sclerosis, cerebral palsy, muscular dystrophy, and Parkinson's disease combined.
- In America, epilepsy is as common as breast cancer and takes as many lives.
- Almost five hundred new cases of epilepsy are diagnosed every day in the United States.
- Epilepsy affects 50 million people worldwide.
- One in one hundred people will develop epilepsy.
- One in ten people will suffer a seizure in their lifetime.
- This year, another 200,000 people in the U.S. will be diagnosed with epilepsy.
- Each year, over 125,000 to 150,000 are newly diagnosed with epilepsy.
- Thirty percent of those diagnosed are children.
- Epilepsy can develop at any age and can be a result of genetics, stroke, head injury, and many other factors.
- For many soldiers, suffering traumatic brain injury on the battlefield, epilepsy will be a long-term consequence.
- In two-thirds of patients diagnosed with epilepsy, the cause is unknown.
- In over 30 percent of patients, seizures cannot be controlled with treatment.
- Uncontrolled seizures may lead to brain damage and death.
- Up to 50,000 Americans die each year from seizures and related causes.
- The mortality rate among people with epilepsy is two to three times higher than the general population.

Surprises

- Risk of sudden death among those with epilepsy is twenty-four times greater.
- Epilepsy results in an estimated annual cost of \$15.5 billion in medical costs and lost or reduced earnings and production.
- Historically, epilepsy research has been under-funded. Each year NIH spends \$30 billion on medical research, but just one half of one percent is spent on epilepsy.
- The Federal government spends much less on epilepsy research compared to other diseases, many of which affect fewer people.

Don't be possessed, seized, or held back.

Seize the moment.

This moment.

That is what many of us are trying to do. As I am trying, I hear many questions still running through this damaged mind.

What is it like saying goodbye to a person who is still alive? What is it like never being able to say goodbye to that person, never being able to grasp or grieve their loss? You knew him or her—or yourself—well. Now you are learning about and accepting the new self or spouse or parent or child or friend or coworker. Now you are trying to learn them. Now you are trying to accept them. You are trying to know them—why they do what they do, how they feel, what you should do, how you feel. You are trying to learn and accept and know you.

Should you help them complete the sentence or remember the name? Should you, as the patient, let those around you locate that word hiding in an unnoticed location in the damaged brain?

Or maybe this is the only you—epilepsy has always been a part of your life.

This isn't a collection of easy answers. It offers ideas but is mainly a confession of the adventure many of us endure. Each day. Each moment. Each word we work to remember.

This is my effort to adjust to the new me.

What's Helped Me

- Rest well and often.
- Drink water.
- Exercise. If walking is all you can do, walk gladly.

Chris Maxwell

UNDERWATER

This is our effort to adjust to the new us.

So welcome to the journey of hidden mysteries and moments of desperation. Welcome to an adventure of pursuing shore while seeking rest amid the unknown. Welcome to swimming among waves in the deep. Welcome to firm rocks, unexpected shallow water, and a sight of unfamiliarity staring back.

Did You Know?

In America, epilepsy is as common as breast cancer and takes as many lives.

source: cureepilepsy.org/aboutepilepsy/facts.asp

Welcome to the cold—of numb hands and feet and faces. Welcome to inner questions of endurance or surrender. Welcome to turbulence of fatigue, exhaustion. Welcome to the existence of feeling worn out, swimming with an ongoing desire to be back in bed. Welcome to the overwork of the brain's functioning region that seeks to pick up the slack from the damaged portion's inability to do its tasks. Welcome to confessions of how the brain battles events like its own versions of tsunamis,

ridges, valleys, slopes, trenches, shelves, seamounts, cliffs, caves, arches, stacks, terraces, currents, and lagoons. Welcome to coming ashore to an unknown beach. Welcome to the world of disease and disability, the world of encephalitis and epilepsy, the world of scar tissue, the world of seizures and medication, the world of an electrical system under construction until forever.

Welcome to life *Underwater*.