Surviving a STROKE

ANDREW FISHER

INTRODUCTION BY ALEX ABOU-CHEBL, M.D.

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Acknowledgments

I dedicate this book to my twin boys, Aleczander and Andrew. You are the inspiration that keeps me strong. At the end of my days I want you to know that it was thoughts of the two of you that gave me the hope and the inspiration I needed to recover from my stroke. You were the beacon of light that kept shining even at my darkest hour.

To Shannon, you will never know how truly strong you are. Thank you for holding my hand through the most terrifying and helpless time in my life, and for your constant fight to get me the help that I needed after I was released from the hospital and we were on our own. Thank you.

To my Mom and Dad, Sandra and Douglas, I am sorry for the constant worry that I have put you through. I am truly sorry for not coming to you when I needed you most. NOTHING was your fault! I couldn't have asked for better parents. Thank you for always supporting me even through the darkest times.

To my brothers Dereck and Skip, thank you for continuing to be my big brothers.

To Dr. James Ramsey, President of the University of Louisville, thank you for the environment that you have

created at your university. You have shown that all life matters and that regardless of a person's position in life or where he or she comes from, everyone is special. You are a man like no other. Our region is a better place with you being a part of it.

To Dr. Alex Abou-Chebl and his staff: quite simply, I thank you from the bottom of my heart for giving me my life back. Thank you for every day making sure I am OK.

I truly love you all.

And finally, to Alec and Andrew: what I want most for you to get from my story is to live by these simple rules:

Truly know the people who love you.

Trust in those people who love you.

Don't be too proud to ask for help when you need it.

Love yourself.

And most of all . . . Never Give Up!!!!!!

Introduction

Alex Abou-Chebl, M.D.

I have written multiple scientific articles, book chapters and the like, so writing is generally not difficult for me. I just sit down and start to write. However, writing this introduction took me several weeks. When I had recommended, almost without thought, to Andrew that he write down his experience, I did not expect that it would have such a profound impact upon me. When I read what Andrew had gone through before, during, and especially after the stroke, I was overwhelmed with emotion. I could not write. The words would not come. I had always considered that what I do daily as a physician was beneficial to all: to the patient, to the family, to society, and for the profession.

While I have always known that the treatments and advice that I give patients are not without risk and are not always easy to comply with, I had not imagined that to comply with my recommendations for his health, Andrew and his family would be brought to financial ruin and

to the desperate choice between paying for medicines or feeding the children. So, I took several weeks to be able to begin writing as I came to grips with what had transpired and I was reminded of a fact I had always known, a fact that I had been taught in medical school: our patients have lives before and after we treat them and they do not just exist when they are in our clinics or hospitals. What we say and do has a tremendous impact on their lives and those whom they love.

That is why this account is so important. When I publish the outcomes of my treatment experience and research, the names of the patients, their professions, and who they are as people are all deliberately, completely hidden. Besides being a law, it is the patient-doctor relationship and the confidentiality inherent within this relationship that prevents me from writing about the patients. It is also more than that.

Medical and scientific writing has evolved over the decades and has become purely scientific. As a result, it has also become completely devoid of humanity. When reporting on experiences with stroke patients like Andrew, I lump the patients into groups based on stroke severity and location and the type of treatment they received. They are further categorized into smaller "subgroups" so that my colleagues can critically analyze my treatment results and replicate them with their own patients. I present the results in terms of how many can take care of themselves after three months of recovery, how many have had recurrent strokes, and how many have died. In essence, I distill their illness and their life into a quantitative, cold, analytical

model. Somehow that has always felt wrong to me. Not wrong from a scientific point of view, but wrong from a human point of view.

Andrew Fisher is more than just subject #35 in my database of similarly-treated patients. He is a man, a father, a son, a member of a community and he has experiences and a story worth telling. I cannot quantify what Andrew has gone through to be where he is today. His stroke was just a fork in the road of a long journey. The stroke was not the journey.

His story is a remarkable story because Andrew is a remarkable man. When I met him, I knew nothing about him as a person. I knew that he was at death's door and that he needed help. I knew that I could help him if he would let me. I was frustrated when he initially turned me down. After all, I had waited for hours at the hospital for him to arrive by helicopter, but more importantly I was frustrated because I could not idly stand by while the stroke was destroying his brain. I had chosen my career path because I knew that for far too long patients with stroke were not treated—and they continue to not be treated—because of a lack of adequate treatments, because of fear, and because of ignorance on the part of patients and doctors alike.

Now I know that when Andrew turned down the treatment he had several reasons to do so. What he went through before the stroke and what he has done with his life since the stroke are truly remarkable. They attest to the power of the human spirit and the power of optimism. They attest to the power of love that a man can have for

his children. Now I know what Andrew was thinking of since I now have children of my own.

The story that Andrew tells is honest and very human. It is also a very detailed telling of a perspective that physicians, patients, and those who are not ill rarely have a glimpse of. Andrew's eloquent recital is very powerful and hopefully can serve as a powerful reminder to us all of how fragile our lives are. It is an important testament to the importance of taking care of our bodies. It is an important message to educate people about the symptoms of stroke. It is an important message to physicians that we need to treat every patient as an individual with a whole history and life that does not include us or illness within it and not just as a number. It is also important to physicians in reminding them that not every patient can be categorized into a particular box, especially patients with stroke.

Andrew had basilar artery atherosclerotic occlusion with brainstem stroke of greater than 36 hours' duration. The medical standard of care was for Andrew to receive aspirin, intravenous fluids, and treatments aimed at preventing pneumonia and blood clots in the lungs. At most hospitals across the USA and the world, nothing more would have been done for Andrew. Even medications aimed at improving blood flow to the brain by increasing his blood pressure would be considered not the standard of care.

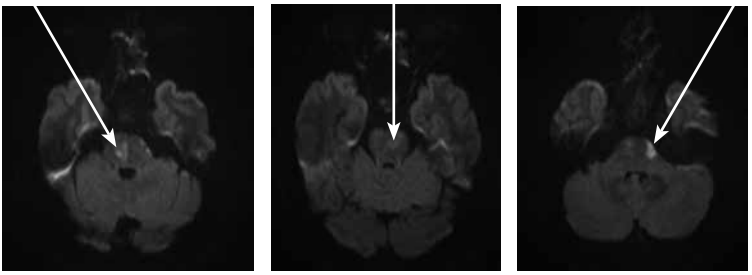
Why? Because no randomized clinical trial has been done to prove that such treatments are helpful. However, there is a great deal of anecdotal experience with some of these treatments with good results. There has also been

experience with bad results. Therefore, many physicians choose not to offer such treatments because they are unproven and our health care bureaucracy tows the line by not approving treatments that have not been proven.

I generally adhere to this philosophy and am a fervent believer in the scientific method. However, as a mentor of mine, Dr. Louis R. Caplan, has so eloquently stated: "When dealing with stroke patients, we must always ask ourselves 'what is wrong with Mr. Jones?'" In other words, when dealing with a unique situation—and most stroke patients are unique—you must consider each patient individually and decide on a unique treatment plan for each patient. This is because there will never be a clinical trial of 35-year-old men with 36 hours of progressive brainstem stroke due to hardening of the arteries leading to basilar artery occlusion.

I have been fortunate enough to have been trained by some of the brightest, most experienced, and most innovative physicians in the field. They instilled in me a deep understanding of the complexity of stroke as well as the confidence to try new treatments when all else has failed. As a result, I have tried to always offer treatment to all stroke patients, if possible.

Therefore, when I met Andrew, I surmised that based on the progressive nature of the symptoms, and on hearing his 37-year-old brother had had a heart attack, Andrew must have hardening of the arteries of the brain. In particular, he must have had a narrowing that had progressed to sudden complete blockage of the single most important artery in the brain, the basilar artery. This artery supplies blood to



A pretreatment MRI scan shows three areas of infarct (stroke), seen as white areas in the pons (part of the brainstem).

the brainstem, the part of the brain responsible for keeping us awake and breathing and for transmitting commands from our brain to the muscles of our face and limbs. This type of stroke is typically fatal with only a 1-2 out of 10 chance of survival.

I had seen many patients like this during my career and before I became an interventionist (that is, learned how to open up brain arteries via minimally invasive techniques), I was often frustrated that they were not treated more aggressively because of a lack of "proof" that such aggressive treatments (for example, infusing clot-dissolving medications directly into the basilar artery or inflating a balloon within it to create a larger channel for blood to flow) were effective. The logic behind this thinking is that aggressive treatment is risky and can be life-threatening, and in the absence of proof of effectiveness such treatments were unjustified.

The flaw with this logic was that if patients are destined to almost certain death or to life in a vegetative or locked-in state, then what do they have to lose? Of course, the physician should not make such decisions but the patient

and family should. I have always felt that if I could devise a treatment plan that was based on a thoughtful analysis of the problem and that was effective in other situations (for example, heart attack), then if I inform the patient and the family of these facts I could ask them to decide whether to have the treatment or not. They would decide knowing that it was unproven and experimental, but it was based on sound therapeutic principles.

Thus, I offered Andrew and his family an experimental treatment wherein I planned to place a stent (a metal mesh tube about 1/10 of an inch wide and ½ of an inch long) designed for the heart in the basilar artery. What made this truly experimental was that so many hours had passed since the onset that there was no guarantee that the procedure would prevent any of the brain cells from dying. To make matters even worse, treatment so far out from stroke onset has been associated with a very high risk of fatal bleeding into the brain.

When I first evaluated Andrew he was having progressive difficulty talking and he had weakness of all four limbs. He was also having a hard time clearing saliva and secretions from his mouth and throat. Yet, he was awake and able to see and hear everything he was told. He was fortunate that some of the small arteries connecting the arteries in the front of the brain were open and able to supply a small amount of blood flow to the part of the brainstem that keeps us awake (the diencephalon). Otherwise, he would have been comatose. Andrew was therefore able to understand the risks and potential benefits of the treatment. He decided against the treatment and so I had

Surviving a STROKE

Raising Awareness

I live in Indiana, part of the Stroke Belt. It's an 11-state area where the incidence of this catastrophic condition and other cardiovascular disease is the highest in the nation. But I knew nothing of the Stroke Belt in March 2009, when at the age of 35 I suffered a stroke that nearly took my life. I was one of the lucky ones.

I was lucky because I was able to get treatment after the normal three- to four-and-a-half hour treatment window. Most hospitals in the country and world cannot and will not treat after this window. If I hadn't been transported to the University of Louisville Hospital, I would have either died or been destined for a dependent life in a locked-in or vegetative state.

I have spent countless hours reading what "experts" say about interventional stroke treatment. I have read all the dangers of having stents placed in your brain and how this is considered radical treatment. Such a large percentage of doctors believe that medication is the best and safest way to fight a stroke. However, there is an ever-so-small number of interventionists, who may be considered "cowboys" or "renegades," who believe you can go in and stop a stroke even after "the three-hour window" of opportunity when

treatment is deemed advisable. The window passes by because such a large percentage of us are not educated as to what to look for when a stroke is in its early stages.

These "renegades" or "cowboys" are said to be putting human life second to their own aspirations and their pursuit of mastering cutting-edge technology. But I believe these doctors are saving lives. I believe they are pioneers in their specialty and will revolutionize stroke treatment as we know it today. I suppose that doctors who proposed treating cancer with radiation in lieu of amputation may have once been thought of in the same way.

What makes my opinion so valuable about this topic? Well, I am one of the large percentage of people that was not educated as to the signs of a stroke. My thinking that strokes only happen to people when they are older nearly cost me my life. Without Dr. Alex Abou-Chebl, University Hospital's director of interventional neurology, and the handful of others like him, I would not be here today to tell you this story. Or at the very least, I would have no ability to communicate it to you.

Yes, I ignored the signs of my stroke as it was happening to me. If I would have been more open-minded and willing to recognize what my body was trying to tell me and had been more educated on stroke awareness, I may have been able to stop my stroke from progressing as far as it did. But because I chose to ignore these signs, I have this amazing story to tell. And because of Dr. Abou-Chebl and the University of Louisville, I am alive to tell it.

I am not here to confuse you with medical terms and theories. I am just one man who is a father, a son and a

brother with what could have been a life cut short, telling you the story of what happened to me in the span of about 48 hours in March of 2009.

My only hope is that after you read this book you will be more aware of strokes and the terrible consequences for not treating them soon enough. I hope to raise stroke awareness so that even if one never happens to you, you will be aware of the symptoms that may be happening to someone you love. With a stroke, timing is a matter of life or death.

Strokes do not discriminate. They affect young and old. No matter how healthy and strong you are it can happen to you. And if you aren't aware of what is happening to you or someone close to you, you will not be able to act fast enough to save a life. Strokes are the number one cause of long-term disability and the third leading cause of death in the United States.

Here is my story.