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The Art of Responsibility

by Mike Falconer



MIKE FALCONER

“I’m not trying to be the Lance Armstrong of the lighting world.”

Lighting designer Edgar Stroke is, like many people in this industry, a busy man. Thanks to a diverse client base, he works as a freelancer on a wide range of projects and shows. Unlike most, however, he juggles his work with battling, researching, and advising on a rare form of cancer: his own.

Stroke was born in Boston in 1958, to parents who had emigrated to the US from Yugoslavia (now Croatia) in 1952. After stays in Boston, Paris, and Ann Arbor, Michigan, the family settled on Long Island. Stroke's father was a pioneer in the science of holography. It was not unusual for the young boy to find lasers in the closet or to encounter Nobel Prize-winners as dinner guests. However, after an affair, his father left the family behind, and Stroke's devastated mother sought solace in a place called The Slavic Cultural Center.

A child of the performing arts

This Slavic Cultural Center was founded by Edward J. Czerwinski with the goal of introducing and promoting Slavic and Eastern European culture to Americans. At the time, some of the most respected theatre work in the world was coming out of Eastern Europe, and the Slavic Center became a well-known culture spot in the New York area. This was Stroke's first serious exposure to the performing arts, and the 11-year-old was soon acting and working as a puppeteer. Eventually, he started running the lights for productions, and, at 14, designed his first show. "I think, from very early on, working in this incredibly stimulating theatre environment, my life path was laid," he remarks.

Ultimately, Stroke would become technical director/resident designer at the Slavic Center, which mounted American and world premieres of plays from Eastern Europe (with American casts), as well as importing directors, designers, playwrights, actors, and entire touring companies from

Eastern Europe. The Center also sent out touring productions around the US, allowing Stroke to learn those skills as well.

By the late 70s, the Slavic Center's production work had more or less stopped and Stroke was busy designing for local bands, running a nightclub, and working as a DJ. In 1978, he was crewing full-time for the band Foghat, performing his DJ act "Devastation Dan" on weekends, and working on a BA at the State University of New York at Stony Brook, as well as continuing to design lighting for theatre and music acts.

In the fall of 1979, Stroke was offered a job as assistant technical director of the brand-new Fine Arts Center at Stony Brook. This new road house included several theatres, a recital hall, and art gallery. When he left in 1985, it was as technical director, after having worked, as TD or lighting designer, with a range of names that included Dizzy Gillespie, The Acting Company, Yitzhak Perlman, and Jessye Norman.

In August 1981, Stroke noticed a pea-sized bump behind his right ear. A doctor diagnosed it as a swollen lymph gland and told him not to worry about it. By 1984, the lump was the size of a golf ball and had to be surgically removed. It was only after surgery that an accurate diagnosis was made: Acinic Cell Carcinoma, a highly rare salivary-gland cancer (there are, on average, only 135 cases in the United States each year). "My case was mishandled from the beginning," he says. "If they had removed the lump in 1981, or even attempted a proper diagnosis before surgery, I might never have had a cancer history." He was advised to get postoperative radiation therapy, so he went to Memorial Sloan-Kettering, one of the leading cancer hospitals in the world. After a course of conventional radiation therapy, the cancer appeared to be gone.

The daily life of Edgar Stroke—lighting designer, medical activist, and cancer survivor

Starting over on the West Coast

In 1985, Stroke moved to Los Angeles to enroll in the USC School of Cinema-Television, with his sights set on directing. By the time he received his MFA in 1990, he had made several award-winning films. During his summers, he worked in various fields, including lighting design, electrics, puppeteering, and television and film production. His diverse skill set had earned him a reputation as someone who could handle whatever was thrown at him.

Around the time of his graduation, Stroke experienced back pain, which was diagnosed as a slipped disc, an injury consistent with someone who routinely found himself in physically demanding environments. Over the next three years, while screenwriting with a partner (as well as video-coordinating on television shows, directing and producing videos, teaching tech theatre at UCLA, designing lights, etc.), his sciatic pain escalated to the point where he had severe problems sitting. In early 1993, during a routine cancer follow-up, a junior resident suggested running a bone scan on his lower spine. (In fact, this is a test which, Stroke says, should have been performed routinely on someone with his type of cancer. It had never been run on him. Now he knows better.)

Stroke's lower back pain turned out to be a huge metastatic Acinic Cell Carcinoma tumor. His original cancer had returned, growing at the base of his spine, between his hips. The grapefruit-sized metastasis had destroyed his entire sacrum, which is the triangular-shaped bone at the bottom of the spinal column, through which nerves pass. The tumor had enveloped all of those nerves; it was essentially inoperable without cutting them and losing various functions. Stroke was the only case on record of this type of cancer in this location.



COURTESY OF EDGAR STROKE

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"That was when I realized it was time to start taking more responsibility," he says. "As soon as I began doing research, I found out that my case had been mishandled in all the early stages. There was an unusual form of treatment, called Fast Neutron Radiation, which should have been used on me in 1984. It had been known since the 1970s that it was more effective on salivary gland cancers, but, when I went back and talked to my original doctor from Memorial Sloan-

Kettering, he still considered it experimental.

"No one can abdicate responsibly for their own health," adds Stroke. "No doctor can or will spend more time on your case than you or your loved ones. That does not mean that you have to replace the doctor; it just means that you have to be informed and know if the doctor is doing the right thing for you."

In the pre-Internet days, Stroke worked his way through medical libraries to research this rare and little-understood cancer on his own. He learned that one of the few places in the world where he could receive Fast Neutron Radiation treatment was in Seattle, Washington. By the time he had returned from his four-month course of treatment in Seattle, he had spent almost all of 1993 dealing with cancer.

Returning to lighting

"It wasn't like a big lightbulb went off in my head," he says. "But I realized that, whatever I was going to do next, I would have to really enjoy it. I was making films and TV shows, but found that, although the financial rewards could be great, there were aspects of the filmmaking world, particularly in Hollywood, that were not so enjoyable for me. There was also a time element; with theatre, you may work on something for a few days to a few

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PHOTOS: COURTESY OF EDGAR STROKE



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Stroke's designs includes concert projects (previous spread) and this production of *Antigone*, above. Opposite: Stroke at work.

months—the same with concerts, in most cases. With filmmaking, as a writer/director, it rarely takes less than a year, and it can take ten years, or more, from conception to completion. With that in mind, I asked myself what work would give me the most enjoyment. The answer was, unquestionably, concert lighting. I also knew that I had an unusual natural talent and love for specifically turning music into visuals and I wanted to exercise that more.”

With the cancer apparently stabilized and the pain significantly reduced, 1994 saw Stroke reinventing himself. For the first time in his life, he specialized in a single area: rock lighting design. He quickly established a list of regular clients such as Pat Benatar, General Public/Dave Wakeling, The Corey Feldman Band, The Buddhaheads, and others. He also did countless individual shows for such clients as DEVO, The Fixx, Marc Cohn, Sonia Dada, The Wailers, Dave Mason, Dave Davies, Will Downing, Jeffrey Osborne, and House of Blues. Of course, like any freelance lighting designer, there was also a fair amount of industrial and fashion-show work, nightclub designs, theatre, and other things. Over the next five years, he expanded his client base and firmly established himself as a rock-and-roll lighting designer.

In April 1999, having recently returned from working with his friend Jeff Ravitz on the Springsteen/E-Street Band reunion tour, Stroke collapsed during a show at the Los Angeles Convention Center; after that, he could no longer walk, stand, or sit. His tumor was growing again for the first time since the Fast Neutron Radiation treatment in 1993. He spent the rest of the year on his living-room floor, unable to go anywhere without assistance. “I had an essentially inoperable tumor, a cancer with no standard successful treatment options, and a bunch of doctors with no solutions,” he says. “I could not be re-treated with fast neutrons, as that would likely cause more damage than help. My cancer seems to go through these periodic growth spurts, and nobody had any idea how to stop it. No surgeon wanted to operate on me unless the potential benefits outweighed the potential deficits. This meant that, until things got really bad, nobody would touch me. It was pretty challenging, with no obvious light at the end of the tunnel.”

However, 1999 was also a major growth year for the Internet; while unable to move, Stroke had found a new way to send and receive information. “I realized that, with the Internet, all my suffering could be translated into a way to help other people,” he says. “I had accumulated a lot of knowledge about this cancer, knowledge that most doctors and almost all patients did not have. I felt that I had a responsibility to tell all that I knew, to try to help as many people as possible.” So he created his own website: The Acinic Cell Carcinoma Information Center at www.aciniccell.org, and an email group with the Association for Online Cancer Resources at www.acor.org, to share his knowledge and experience.

By late 1999, Stroke's tumor had grown even more, radically impairing his urologic functions. He finally found surgeons who

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were willing to operate. Unfortunately, they were only able to remove a small percentage of the tumor. But they also installed two 3.5" lag bolts, connecting his lower spine to his right hip. This stabilization worked well and he was soon able to stand, walk, and drive again.

Although chemotherapy is usually ineffective on Stroke's type of cancer, the year 2000 saw some experiments in this area, as well as some alternative approaches, including various vitamins and supplements. Although the tumor had now extended into both hips, it appeared to be stable.

Finding the balance

Despite some physical impairments, Stroke was able to think about designing rock tours again. But it wasn't quite so simple. "One philosophy of my life is responsibility," he comments. "I'm really big on responsibility and really anti-irresponsibility. That covers everything from show business to medicine to driving. I have always taken my showbiz responsibilities very seriously, and done my part to the fullest, always giving 100%. Now I feel I have a new responsibility to spread my knowledge about this cancer and to do more research to really help those other patients out there."

So Stroke's life is now a juggling act: "I constantly have to make decisions on whether to focus on cancer-advising, rock lighting, or saving my own life. This happens on a regular day-to-day basis. It often leads to personal frustration about the shows or tours I cannot take. I see a client or ex-client or musician I love,

going out on tour and I want to call them, but I have to restrain myself most of the time. Consequently, in order to fulfill my creative needs, I do a lot of one-offs and smaller shows in LA, often for little or no money, just to be able to do something artistically rewarding. It can be very frustrating, because I know that if lighting was all I was focused on, I could be doing much bigger shows and tours, and really making a statement. On the flip side, when I spend too much time on a showbiz project, I end up frustrated that I haven't finished the work on the cancer website. I really need a 72-hour day, or three of me!"

After being stable for four years, Stroke's tumor began growing again in 2004, leading to constant, severe symptoms and a new round of various painkiller regimens. This meant he had to return to seriously research new treatments. It's an uphill battle, as no one does basic research on this cancer or its treatment, so he is now searching for the next experiment to try on himself. "The current goal is to find a medical treatment, a drug, or combination of drugs, that would get rid of the cancer completely and forever," he says. "But I know enough about what's out there to know that the odds of finding this are pretty low. Yet, I still will likely have to be a guinea pig again and try something." He adds that the research doesn't give him quite the same stimulation as working on rock shows. "You would think when I am having a major cancer crisis, that it would take priority," he says with a laugh. "All the people around me would suggest that it should. But in point of fact, it doesn't always. I sometimes have

this burning desire or burning sense of responsibility with a showbiz client or project. I do, however, get daily emails, if not several times a day, from cancer patients or doctors, and I try and respond to them the same day. That usually comes first, before everything else."

Stroke's experimentation with pain medication is currently working and recently allowed him to work for a month on his regular stint as designer/TD of the Yosemite National Park Theatre Programs, design the annual Corey Feldman Band birthday show, and handle a number of dates for punk rock client Naked Aggression. "I'm not trying to be the Lance Armstrong of the lighting world," he laughs. "I'm just trying to fulfill my artistic and creative desires, as well as my responsibilities at the same time. If I was just doing what I want, I would be working on some kind of show or production almost all the time. As much as I feel I have a responsibility to do it, cancer research and cancer websites are not my idea of a good time. I do hope to still take my concert lighting career to the next level. I have numerous artistic desires I still want to fulfill and I don't give up. I've proven myself to be pretty resilient by this time. I view each new medical challenge as yet another project I need to find creative solutions for, and I seem to keep getting through them. That's something theatre and rock and roll have taught me very well. You have to solve all the problems, no matter how challenging. And you need to get it all done by the time the houselights go out!" ☺