Vital Signs

Wondering what enables some people to survive when the odds are against them, POZ talked to 18 extraordinary individuals—two are HIV negative, and 16 live with HIV—all of whom have prevailed despite great adversity. Here, we share the traits (and tactics) they find most useful in enduring their battle to survive.

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All of us were born kicking and fighting to live. But we have become used to the soft life. We have become creatures of comfort. We dislike inconveniences and discomforts. So what happens when we are faced with a survival situation, with its stresses, inconveniences and discomforts? This is when the will to live—placing a high value on living—is vital. The experience and knowledge you have gained through life and through your training have bearing on your will to live. Stubbornness, a refusal to give in to problems and obstacles that face you, will give you the mental and physical strength to endure."

Sound familiar? Those of us who live with HIV or have been challenged by other life-threatening situations know all too well the truth of these words. They come not from some self-help manual but from the first chapter of the *U.S. Army Survival Manual* (required reading for all new recruits)—a guidebook dedicated to the finer points of staying on the planet. It is maybe not surprising, then, at least to those of us practiced in the art of trying to stay alive, that the manual begins with an exploration of the qualities that most people inherently possess.

According to the U.S. Army, there are several key qualities essential to increasing your chances for survival. They are: being able to make up your mind; being able to improvise; being able to live with yourself; being able to make a good thing out of a bad thing; remaining cool, calm and collected; hoping for the best but preparing for the worst; having patience; being able to understand and predict what other people will do; and understanding where your fears and worries come from and knowing what to do to control them. Reading the list and thinking back on my own struggle with survival, I realized that all of these are qualities I've called upon and, perhaps more important, that they are qualities I always possessed—though I didn't know it until I used them to fight for my life.

Regardless of how long you have been dealing with HIV, whether you're newly diagnosed or a 20-year vet of the virus or how relatively easy or arduous your struggle, if you are reading this, then you are already a survivor. You don't have to go to boot camp to learn how to survive. In fact, none of the people *POZ* talked to see themselves as particularly designed or trained for survival; they continue to live because they don't want to exercise the alternative option. Of course, death

will eventually come for all of us, no matter how courageous or determined or "skilled" at living we become. The inevitable demise of so many brave, powerful souls who are already gone is proof that no one gets out of life alive. But while we recognize that ultimately we will all succumb to death, there are some people whose tales of survival serve as inspiration and reminders for how to stay strong.

Meet Carl Dellatore, an HIV positive textile designer who, 21 years ago on February 7 was given two years to live. On February 7, 1987, Dellatore, now 45, celebrated beating the two-year mark by having the word *hope* tattooed on his left bicep. The word captured the philosophy that had helped get him through. "Knowing that every day there's hope for the next if you can just get through this one keeps me going," Dellatore says. Today, those feelings of hope have evolved into a more defiant mantra. "I say to myself every day, 'I'm not having it. I'm just not having it.' My therapist wants to put that on my tombstone," he says with a laugh.

Another man recognized for his ability to live through life-threatening conditions is Benedict Allen, an HIV negative British explorer best known for his death-defying solo journeys in such places as the Amazon Jungle, the Gobi Desert and Siberia. There was the time gold miners in the Amazon threatened to slit his throat and he had to walk hundreds of miles without food or supplies through some of the densest rain forest in the world. There was the time his team of sled dogs ran off an icy cliff in the middle of the night (they all survived too). And there was the time he endured the "crocodile initiation ceremony"—in which a New Guinea tribe lacerated his body to make it "as tough as a crocodile." Allen says, "When I had brushes with death, I discovered for myself a new proximity to life."

Having a greater appreciation for life as a result of facing death is a phenomenon familiar to Alan J. Stein, MD, an HIV negative AIDS doctor who practices in Park Slope, Brooklyn, and who was diagnosed with cancer in his neck in 1993. There was little hope for his recovery, and the postsurgical treatment nearly killed him. But, supported by his wife, Mary, a nurse, he soldiered through, and today he shares with his AIDS patients what he learned about avoiding the hereafter. "A lot of the people I see are newly diagnosed. They come in shaken, with the expectation that they're going to die soon. I tell them I know how I felt when I was in a similar situation. I tell them, 'If I could do it, you can do it.'"

Then there is David Schachne, HIV positive since 1984, who has never taken a med in his life and is in prime health. His ancestors survived the Black Plague and the Spanish flu, and he has survived two bouts with unidentified viral infections earlier in life. Is it good genes that protect him? His vegan diet? Luck? Talking to the vibrant 48-year-old, you can't help but consider his outlook and energy. "I'd been told twice before in my life that I had a terminal condition and made it through. So when they told me I had HIV and was going to die, I just refused to believe the hype," he says.

In addition to Dellatore, Allen, Stein and Schachne, *POZ* talked to 14 others who have survived HIV hoping to identify the spirit of survival. Though they hardly knew it, each of them could have written as effective a survival manual as that of the Army. While clearly there is no magic solution

to extending one's life, there are tried-and-true approaches that can increase your chances for longevity. We found that their most effective and commonly employed mental secrets can be grouped into five main categories.

Accept the Situation

Nicole Guide, 42, a survivor of HIV since 1990, is an AIDS educator who coaches the newly diagnosed. "Part of what helps me face the fact that I have HIV is the realization that it is not the worst thing that I could have," says Guide, who is currently in fairly good health despite being positive and having diabetes. I know people who have HIV as well as other physical conditions that are more difficult for them. It helps me to know that, given the way my body is handling the HIV up to now, I could have something that would make me feel much worse."

Dr. Stein says, "You need to accept that life is going to be different with HIV. You have to release control. When you let go, your fears and anxieties will fall away; you'll be stronger. When your energy is not diverted into fear, you can direct it into activity and dealing with the problem."

Alfredo Millán, a Puerto Rican–born dancer, 44, positive since 1995 says, "I've always been very centered. It was just a matter of accepting my diagnosis and making changes in my life. I am used to fighting. Living in New York City has taught me how to survive. You have to face the fact that life is brutal. The question is: 'What are you going to do about it?' In the darkest moments of my life, I remember that I've come through things before and I will again. I want to know what this life has in store for me. I am going to find out."

Charles Green, 39 and HIV positive since 1995, says he was a basket case until friends put him in touch with an HIV outreach agency in Connecticut called Bread and Roses. "I started participating in one-on-one counseling, then support groups; then I volunteered. As a result, I learned I don't live with the virus—it lives with me."

Adapt and Be Creative

Because of his medical condition, Dr. Stein had to change his diet. Adapting, he says, is a matter of retraining your habits and getting into the right setting and hooking up with the right people. "So much of what we do is habit. If you can step back and realize that, you can change your habits for the better."

Adaptation was also the key for Randy Near, 56, who's been HIV positive since 1984. After about six months into any new treatment regimen, his meds always seemed to give up. "I would develop resistance even though I was taking them as I should." He tried various regimens but says that when they failed, he had to rethink his approach. Eventually, a course of digestive enzymes helped most. "I believe that because my body wasn't properly absorbing the meds, it was as if I wasn't taking them." The enzymes helped his digestion, and he has been on the same regimen successfully for two and a half years.

Carlos Escoto, 43, found a new career after he found out that he had HIV in 1986. The professor of psychology got his doctorate in 2002; now, he's working on his second master's. "You can't cling

to something that isn't working. You have to let go," he says. "What helps me most is the ability to adapt, to cross each bridge as I get to it."

Be Proactive and Decisive

Taking charge of your life can counterbalance the uncertainty caused by living with HIV. "It's very important to believe that there's always something you can do. You must control your own destiny or someone (or something) else will. The mind determines everything—including what you believe," says Allen.

Dr. Stein agrees. "I never felt like a victim. I never asked, 'Why me?' or said, 'Poor me.' I said, 'It's OK. I've got this, and I'm gonna deal with it.'" He says his patients often say contracting HIV forced them to straighten out their lives. They stopped drinking or got their relationships back on track. "When each day is precious to you, you're more likely to make it a positive experience," he says.

Barbara Powell, 52, was a blues-rock singer before she contracted HIV in 1990. Working in what she calls the AIDS-phobic world of music after her diagnosis, she feared disclosure and had trouble singing about sex, drugs and rock 'n' roll. "I didn't feel very sexy," she says. In 1998, she left the business and didn't get onstage again until 2001, when she sang Leon's Russell's "A Song for You" before disclosing to coworkers at the New York City club CBGB. Since then, she has taken control of her disclosure—by telling others when she decides it's appropriate. "I feel that my activism is just to be myself and to let people know that people like me get this disease."

Working as a resident adviser in a methadone clinic, Mark Flores, 42 and positive since 1997, cites his involvement in AIDS work as a lifesaver. "Doing community service made a huge difference in how I see myself. Action gives me power over something I don't really have power over. I teach this to AIDS patients. I suggest they go for a walk or do the dishes—anything just to get moving. When patients tell me, 'I am sick; I have HIV,' I say, 'Let's look at that.' Words have real power. If you're walking around saying. 'I'm sick with HIV,' maybe you want to be sick. I say, take command instead and say, 'I am living with HIV.' "

Being an HIV educator helps Anthony Raiola, 42 and positive since 1996, thrive. "I tell HIV positive people that getting, understanding and accepting the facts as best you can is the key to living a mentally and physically healthy life. The more information you can get, the better you'll feel. Facing the facts is a great way to feel empowered." Joe Norton, 44, who works with Broadway Cares as its education outreach director, agrees. Positive since 1992, his activism forces him to confront reality and makes him feel like he's in charge of his own fight and helping lead others too. "It's great to be a person with resources, great to be part of the solution and fight instead of being part of the problem."

Take One Day at a Time

Dr. Stein recommends trying to survive bit by bit. "I liken [survival] to running a marathon. I imagine the finish line but focus on small increments of effort. Your concentration and desire can get worn down easily if you focus too far ahead."

Ross MacLean, who is 52 and was diagnosed in 1990, says, “You have to do what you can do, and sometimes that’s nothing other than holding on tight and riding it out. Our culture tells us we have to act, but sometimes we just have to be.”

Former hairdresser Vinny Allegrini, who is 57 and has been positive since 1989, says, “Giving up has never entered my mind. More than once, my doctors have said, ‘Your chances aren’t good.’ Each time, I’ve said, ‘I’m not going to let this get in my way. One day at a time,’ I say. Today was a good day. Tomorrow’s another day. I dream each day of returning to my passion of cutting hair.”

Trudging through the Amazon, Allen used tricks of visualization. “I couldn’t bear the thought of walking 100 miles, but I could bear the thought of walking 100 paces,” he says. “I would put a little notch on my walking stick each time I counted to 100. Other days, I imagined I was building a castle. With each hour that passed, I put another brick in the castle. I was fortified, thinking of this strong structure. I could almost feel the cold of the granite that would protect me. The castle kept getting bigger and stronger every day.”

Keep a Positive Outlook

Maintaining an upbeat attitude no matter what life throws at them is key for all of the survivors. Their ability to buoy themselves up in the face of adversity, finding hope where little exists, is key. Greg Mitchell, 48, believes he doesn’t have the luxury of self-pity. Positive since 1989, he practices a “healthy denial.” Though he is on treatment and takes his health care and professional life seriously, he never lets himself get bogged down by the weight of HIV. “It’s important to get out of the house. Go have sex. Enjoy a dinner of steak frites!”

The day Michael Palumbaro, 63, was diagnosed in 1987, he went to a “die-in” sponsored by ACT UP. “They traced the outline of my body on the ground,” Palumbaro says. “From that day forward, I have believed that I can be as healthy as I want to be. I stopped drinking and smoking to give my body a break because HIV wasn’t going to give my body a break. I feed myself good, nutritional food, and I practice Zen Buddhism. I do alternative medicine, acupuncture, chiropractic, Chinese herbs, Reiki, massage and tai chi. I never worried that there was no cure yet. I always believed I could keep myself well.”

Steve Hemraj, HIV positive since 2002, says, “If it was not HIV, it would have been something else. So what the heck? I will live until I die, and planning for my future is living for my future. I am now 35, and I will be around way after 70—so I’d better figure out what I want to do with the next half of my life. I chose to return to school and am in college. I will not stop pursuing my happiness and fulfillment. If I have to die, then I will, knowing I fought a good fight.”

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