

“Staying on Top of Hepatitis C & Heart Disease” Sanjiv s Story – Updated August 2010

This story is dedicated to everyone who has faced the challenge of chronic, life threatening diseases, their loved ones who support them through the trauma, and the health care professionals who work tirelessly for this cause. Above all, it is dedicated to my tough and loving life partner Kavita, without whom there would be no story

Sharing my story

A wise man once said “Disease is what you have and illness is how you react to it.” 180 million people worldwide are infected with hepatitis C and over a billion suffer from coronary heart disease. Most patients share their experiences after successful outcomes. I want to share mine as I traverse my journey because I want to offer hope for those of you who are finding it difficult to cope or losing the will to fight. Sharing is therapeutic and I know I will be helping myself as much as you.

I turned 50 in March 2010. I do not yet know the outcome of my long, arduous, test of endurance. But I do know that after two heart bypass surgeries, over 5 years of aggressive therapy for HCV comprising over 280 weekly shots of pegylated interferon and thousands of ribavirin capsules and other drugs, I still have the motivation to fight.

Let me start at the beginning.

Discovering My Heart Disease – March 1989

In March 1989, I was 30, had a lovely wife and two young kids, an active professional life, and was seemingly in great physical shape. Then, after playing a game of squash, I suffered from acute breathlessness and a pain in my left arm. The EKG that followed was abnormal. My cholesterol was a scorching 347 with an LDL of 252. I could manage only 5 minutes on the stress test and an angiogram confirmed that all of my 3 coronary arteries were 90 to 100 % blocked in more than one place. I needed bypass surgery immediately. The news was a huge shock for all of us. My wife, Kavita, is a doctor, and she probably realized the gravity of the situation more than I did.

My First Heart Surgery: April 1989

I vividly remember the day before my heart surgery. I was asked to sit up as the barber prepared me for the surgery. As I watched him shave my chest, the reality of what was coming hit me hard.

When I surfaced, I was in a cold recovery room, connected to multiple monitors with electrodes running across my chest and ending in an IV line on the back of my hand. A huge pipe had been shoved down my throat making it parched and swollen. I was overheated from all the drugs pumped into me and my body hurt unbearably. I remember a nurse leaning close to me and saying I’d had a ‘successful quadruple heart bypass surgery’. I drifted in and out of consciousness, reassured only by the faces of my wife and mother, both of whom hadn’t left my bedside.

Recovery was long and slow. With the passage of time and as I gained strength, my optimism grew. After all I was young and in good shape, cardiac care had made huge strides and there was no reason to think that I couldn't put this behind me and get on with my life. I was determined to work hard at making this happen. Regular walks and yoga, a low fat strict diet and plenty of rest – I started changing my lifestyle for the better.

I had no idea that the blood transfusion given to me during surgery had sowed the seeds of what would become the greatest challenge of my life. I had been transfused with blood contaminated with the hepatitis C virus!

The Volcano: My Discovery of HCV - March 2005

In the years that followed my bypass, I was proud of myself for 'pulling it together.' I felt good, my personal and professional life was great – the surgery had faded into a faint memory. When I look back now, I see that I overlooked the distress signals my body was had been sending me. I had been carrying the hepatitis C virus for 16 years and my liver was damaged. From 2002, I felt aches, pains, fatigue and nausea off and on, but I ignored these warning signs. Does that sound familiar? I have spoken to so many people who have done the same thing. When you're flush with the triumph of having beaten one disease, you simply cannot accept that something else can go wrong.

Ultimately, the symptoms became debilitating. I had no energy. I felt weak and sick all the time. I was not sleeping well and had frequent spells of dizziness and tachycardia. I finally went for a complete medical check-up in March 2005. This included a hepatitis C antibody test.

My test results were a disaster. My liver enzymes were very high (ALT 160, AST 105 normal range < 30) and I was HCV positive. What was worse was the fact that I was Genotype 1 (much more difficult to treat) and had a high viral load of 2.7 million copies per ml. A liver biopsy followed, and those of you who have suffered through one will know what a horrible experience this is. I was poked five times to get a sample and it's hard to say what was worse – the physical discomfort or the mental stress. The biopsy revealed that my liver was extensively damaged and I had fibrosis stage III (bridging fibrosis). I was just a stage away from liver cirrhosis or liver cancer.

I was in shock. I had done everything right for so many years. I had worked so hard to stay healthy – it all seemed deeply unfair. A million questions were racing through my mind. How much time did I have? What were my odds of beating this monster disease? How fast would the liver damage progress? Would I get liver cancer? Did I need a liver transplant? What would happen to my career? To the future of my family? I felt bitter and wronged and an old saying kept coming to my mind "How do you make God laugh? Just tell him your plans!"

Kavita and I started researching hepatitis C. We talked to many medical professionals and read everything we could lay our hands on. The picture that emerged was very bleak. This was a 'silent epidemic' - the leading cause of liver transplants and more people were going to die from hepatitis C than from AIDS. The longer the virus remained in your blood, the worse your chances of recovery and I had carried it for

16 long years. The success rate for treatment of Genotype I was very low and the few known drugs had terrible side effects.

As I learned more, I became increasingly fearful. This fear was nothing like any sensation I had felt before, it had a whole new dimension. It made everything stack up differently – regular, day-to-day worries paled into insignificance. Looking back, I see how easily I could have let the situation paralyze me completely. I was inches away from slipping into an abyss of self-pity and depression but thankfully that didn't happen. Somewhere in that cloud of fear, I found a glimmer of strength. Fear can be a great motivator and I used it to push myself, to gain the momentum that I needed to fight. Kavita was a huge positive influence at this time. "It's natural for you to feel this way, we will beat this together" she said.

'Feeling infected' is one of the strongest emotions that almost everyone newly diagnosed with hepatitis C feels. The thought of having infected Kavita or the children petrified me. Everyone was tested immediately and thankfully the results were negative.

Kavita and I plunged further into our research and I started to get a better picture of the disease. It seemed that hepatitis C, just like heart disease, is not a death sentence until your liver is extensively damaged! Still, I could not find anything that said there was a cure for patients like me who were Genotype 1 with liver damage. I did, however, find many articles that said there was no cure!

First Attempt with HCV therapy – June 2005

My doctor recommended 52 weeks of therapy comprising of a weekly injection of Pegylated interferon & 1000 mg of ribavirin taken daily. Having learned about the side effects I admitted myself at a hospital to initiate therapy. After approx 4 hours of administering the injection, I experienced high fever, body aches, and acute shivering, i.e., the body's reaction to the drug. These persisted for a few hours and then I drifted into sleep as my anxieties of the therapy were released and I felt comforted to have begun my journey.

Over the subsequent weeks, I learnt to manage the harsh side effects of the therapy while leading a regulated lifestyle. Everything seemed to be working well for me; I became HCV undetectable within 12 weeks. However, when I was close to finishing the therapy, I was diagnosed virus positive. This was a big setback; after enduring 50 weeks of therapy I was back to naught and naturally I was dejected!

Second Attempt with HCV therapy – The Tsunami – May 2006

I was not willing to surrender or let my failure derail my plans. After seeking medical advice I restarted therapy with the second brand of Pegylated interferon and Ribavirin. There are differences in the mechanism of action of the two brands and this motivated me to initiate another attempt. Moreover, having learned that interferon therapy is protective to the health of the liver, I felt that continuing would at the very least halt the progression of liver disease.

Once again, I became HCV undetectable within 12 weeks of initiating the therapy. I was well on track to continue therapy to 72 weeks but it was not to be. This time the road block came forth in the 57th week. I vividly remember those days I was feeling really weak, breathless and found it difficult to continue with my already reduced daily activities. Suspecting angina, i.e., strain to the heart muscle, I underwent a

cardiac evaluation including an angiogram. To my utter dismay the results revealed that my heart bypass grafts (done 18 years ago) were completely blocked. My cardiologist recommended repeat heart bypass surgery. Repeat heart surgery is a riskier procedure compared to the first one. Moreover, being on aggressive HCV therapy for a continuous duration of 107 weeks and 18 years older since the first heart surgery, I was compromised, physically weak, and anemic.

Repeat Heart Surgery Experience - July 2007

My heart surgery was scheduled for the first week of July 2007. Memories of the first bypass surgery came back and this helped me mentally prepare for the second “big day” in my “first life.” The night before the surgery I prayed to God to help me through the forthcoming period; both the vital organs of my body, i.e., my heart & my liver were challenged. Many questions ran through my mind but eventually I passed out into deep sleep. At some unconscious level, I was ready for what I would have to face within the coming days and it seemed to me that “I was determined to fight.”

Surgeons are like Gods before any major procedure, as one feels that they control the outcome. I remember being under anesthesia for roughly eight hours, and, when I came to, it was a replay of my first heart surgery experience. Kavita & my mother were standing by my side and my mother was holding my hand. I deeply understood how she felt looking at me in that state; she was overflowing with maternal emotions yet remained poised for my sake. I had come from her chromosomes, her DNA; every particle & cell belonged to her, and when I was a baby she had counted my breath at night. She thought she had gotten me through the hard part, the earlier formative years of my life. She had tragically lost one young child at age 22 (my youngest brother) to asthma and was now looking at me in this condition; being highly spiritual her faith was challenged to the core.

Having had my share of hospitals in my life, I realized that the thing they don't tell you is how violated you feel. Your body is no longer yours, it belongs to the nurses and the doctors, and they are free to probe you at will and force things into your veins and other openings. The catheter was the worst: it ran up my leg into my groin, and having it put in and then taken out was agonizing. In a way, the small hospital procedures are always the awful part of an illness. I remember looking at myself in the mirror one week after my surgery. What I saw reminded me of death; my eyes protruded, my skin was pale and it was as though my body had diminished: my muscles were smaller, and flaccid. My bodyweight was down to 49 Kg (compared to 65 Kg prior to starting HCV therapy). My hemoglobin count had fallen to dangerous levels of 7.4 gms/dl and the experts gave me blood transfusions to replace blood lost during the surgery. I was devoid of any strength and was in no condition to even stand for more than 2 minutes; when I coughed my chest hurt as my sternum had been cut open a second time to allow the surgeons to gain access to my heart during the second surgery and the incisions had been sutured with steel wires. I hadn't gone to the toilet for 4 days which added to my discomfort. At that point it dawned on me and I realized what it meant to lose one's health and to be violently sick!

Difficult times pass if you hang in there with courage; it is the spirit that enables one to encounter danger with firmness and without fear. My recovery each day was slower and very gradual compared to the first heart surgery; but little by little, I recovered and was getting back into a daily routine, mentally relieved, assuming that my medical challenges were over; I thought that I had beaten the HCV (being HCV

undetectable prior to my heart surgery); and now after the surgery I also boasted of a freshly lubricated heart. I believed that life ahead would be much better for me.

October 2007 – The Craters

In the fourth month after the bypass surgery, while recovering, to my utter dismay I relapsed and the HCV virus rebounded to a high level of 16.7 million copies per ml. Once again, a massive setback to my plans! It is known that patients who fail interferon-based treatment typically have few or no treatment options, and are at risk for progressive end stage liver disease.

Third Attempt with HCV therapy – October 2007

Despite another setback I resolved to take my challenges head on. However; I had to do something different compared to my first two attempts; if I did the same thing again how was I to expect a different result? After consulting with the best in October 2007 barely 4 months after my heart surgery, I started double dosage pegylated interferon therapy (2 injections a week). This time I planned to continue therapy for a longer duration of 72 weeks. For the first 24 weeks I took 200% of regular dose of interferon and 1200 mg of Ribavirin. Then for 12 weeks I tapered it down to 150% of regular interferon dose and 1200 mg of Ribavirin. Thereafter, for approx 36 weeks I was on the regular dosage of interferon and 1200 mg of Ribavirin. I became virus undetectable by the 6th week. I continued for 72 weeks but somewhere towards the end of the period I was diagnosed as “positive” with detectable levels of HCV virus. Yet another setback!

Fourth Attempt with HCV therapy – July 2009

Battles are first won in the mind. Despite repeated setbacks my faith in getting rid of the virus permanently remains intact. Translating this into action; I started therapy for the fourth time in July 2009. This time, under guidance from a senior hepatologist I added “Nitazoxanide” to the normal cocktail of Interferon & Ribavirin. Nitazoxanide is an antiviral and has proven to yield higher results when combined with interferon and Ribavirin (reference Stealth clinical trial). As I write this, I have completed 55 weeks, and my 48 weeks results indicate that I am virus undetectable. I was virus detectable for 12 weeks after starting but persisted with therapy to become virus “undetectable” around the 24th week. I will continue therapy for 72 weeks. If this attempt isn’t successful, my next attempt will occur once the oral protease inhibitor telaprevir become available in 2011. Telaprevir promises to be an effective solution for the HCV community.

The Present Day – August 2010

From everything I know, each person’s journey on treatment is personal and will differ from others. I have endured over 280 weekly shots of pegylated interferon and consumed thousands of ribavirin and other capsules in a space of over 5 years (the recommended dose is generally 48) and excessive toxins have been built up in my body during this phase. My body weight is down to 50 kgs from 65 kgs since I started the therapy. HCV therapy (akin to chemotherapy) doesn’t just kill the HCV — it affects the healthy cells, too. It attacks my muscle, my skin, my teeth, and the linings of my throat and my stomach, and leaves me vulnerable to infections. The long duration therapy has robbed me of healthy blood cells and has cut down my hemoglobin count. Hemoglobin transports oxygen to the vital areas, and a normal value of hemoglobin for a healthy person is about 16. I am down to 9.8. My immune system is

compromised, and I have what the doctors called “neutropenia,” my white blood cell count is down to 2800 Cells/cu mm which makes me highly susceptible to infection. I have a high ESR count (a marker for inflammation) and a positive genetic marker “Lipo A” which makes me vulnerable to coronary artery disease. There are other side effects of the therapy that I endure including body aches, nausea, low-grade fever, mood swings, dry skin, dry mouth, tooth decay, skin rashes, malaise, abdominal discomfort, constipation, sleep disturbances and so on. There are times I don’t want to talk, eat or be bothered, i.e., “downtime.” In my strong emotional moments I seek an answer; when will I get an opportunity to rebuild my health?

Living with the ongoing assault of HCV therapy, and having had multiple medical procedures for my medical challenges makes me feel as though I have been run over by a bull dozer and thrown into an abattoir. Moreover, I have the physical scars to show; a number of surgical masterpieces run from various parts of my body to various other parts; a scar that stretches from the left side of my groin to my left ankle, another scar that runs from the right ankle to my right knee, a third scar from left wrist to the elbow; but the real jewels are two deep scars that run down my chest (from the collar to the middle of my chest) which allowed the surgeons to gain access to my heart by cutting open my sternum during the two coronary bypass surgeries With constant pains, aches and malaise it seems that I have had flu for over 5 years ...the combined effects of therapy, surgical interventions, a damaged liver has left me physically depleted.

Each attempt at therapy went by slowly at first and then moved into an eventual rhythm. I work to ensure that I get out of the house each day and follow a healthy disciplined routine. In regard to my work (I own and manage a financial services Company in India) my work has required major adjustments since my diagnosis with HCV. The treatment causes me to be tired and not able to deal with the typical long hours and the day-to-day operational issues of managing a successful consulting business.

I begin each day with a morning walk; in addition I practice yoga & meditation. I also have a masseuse who helps me relax. I eat a simple, low fat diet. My daily routine including my occupation is invaluable in helping me deal with the treatment side effects. A 25 minute meditation routine each morning helps me accept my circumstances and face each day with a level of zest, hope and joy! Staying involved with a routine of healthy habits, family and work helps me tremendously.

Hope & Support

As I reflect on my life, I believe that I am “truly blessed” in that I have been saved every time before disaster has struck. At age 30, I was diagnosed and treated for heart disease before I became the victim of a fatal heart attack, the probability of which was very high. Then again, while going through the HCV therapy I was diagnosed with the need for a repeat heart surgery and was operated upon before irreversible damage occurred and left not strong enough to participate in the HCV therapy... Moreover, when I was diagnosed with HCV in 2005 my prognosis would have been disastrous if I was discovered to be co-infected with HBV and HIV or if HCC (liver cancer) had set in my liver. I consider myself very fortunate that today I am in a position to be hopeful and able to participate and gain from my journey. I believe that I am “blessed” and have a fantastic support system comprising of my lovely life partner Kavita (a medical doctor by profession), my parents, my two boys, Rohan and Raghav (picture appended)

and many friends. I have learned the attributes of a positive attitude from my father, the virtues of believing in God & spirituality from my mother and the commitment to serve from my life partner Kavita.

My Gains

What I have gained from life in 50 years is much more than what I have lost in the past five managing health challenges. Each major setback may have initially shaken me up but in hindsight it has provided me with an opportunity to introspect, take positive action and to do my best in situations within my control. These trials have helped me to cultivate a strong sense of discipline, the will to fight, the ability to understand what is important and what is not. During this period I have emerged stronger and positive in my approach. I am in control of my life and am mentally at peace. Though I cannot predict the future, but on this day as I share my story “I feel on top and triumphant” and that to me is more important than surmising the future chapters of my story! I believe God’s hand, my family’s love and my own endeavors will keep me going! Best of all I feel clearheaded and have a general calmness, which wasn’t so when I started my journey.

Anybody can get a disease and they may do all the right things; after managing the tougher challenges in life many issues seem trivial. They just seem small. “How has all this changed me? The question is how hasn’t it? During every setback I’ve encountered many questions and thoughts of self pity; but you learn to embrace the challenges; when life presents you with challenges it also presents you clues of strength, you may chose to pick the easy route which requires you to do nothing but surrender, I was fortunate that I took what was offered and decided to fight like hell and this, I believe, makes all the difference! Your past experiences shape you and each experience has its own effect. I have learned what it means to be in control, make the best and give it your best; it’s not about the disease; it is a paradigm, a way of life!

During our lives we are faced with different questions; we experience setbacks, and learn to defend ourselves, fight and sometimes just try to stay upright to have hope. These situations test us physically and mentally, they test our perseverance, endurance and even our relationships. I understand this today; there are no shortcuts or free lunches in life; you have to pay the price, moreover, you don’t get it all. I have realized that it takes years to build character, faith and trust and until you have logged hundreds of experiences both positive & negative you just don’t get it!

The physical aches, pains and side effects of HCV and its therapy don’t bother me anymore, because I am conditioned to accept and manage them along with the associated “downtime.” The more I think about it, the more my journey seems a marathon to me. Only the distance changes and the climb becomes steeper; every time I feel that I am close to the finishing line, it seems to be taken away out of sight; it is unsettling and I am caught unprepared. I am used to running low on my body condition and have had many bumps & grinds on the way; but there is a belief that there is a cure for me. I have to climb the peak a few more times, God tells me, which requires a grueling physical & mental effort. I get progress reports from routine medical tests every few months; some good some not so good! However, the big difference between the day I started and the present day is that I try harder than I ever did in the past. During my marathon, I think about my occupation, my livelihood, my responsibilities, and making it through. The idea pumps me up; winning my health back and enjoying 15 healthy years of my life with my life partner

will be my biggest victory! I am focused on getting on with it, as long as I follow my discipline & routine I am in control & healthy!

I am a student of Coronary Heart & HCV disease. I read extensively on the subjects I deal with: heart, liver, on coping emotionally, meditation, spirituality, human traits, behavior, motivation, attitude, I am receptive to consider options, I have learnt about milk thistle, flaxseed oil, wheatgrass, soy, garlic, COQ 10, Vitamin D, selenium, alpha lipolic acid, NAC, turmeric, a host of other antioxidants, yoga, meditation, ayurveda, aura healing, diet, massage, lifestyle, exercise and so on. I follow clinical trials and their outcomes. The more research I do the better conditioned I get; knowledge is always more reassuring than ignorance: at least you know what you are dealing with!

Answers to questions; Why me? What are my chances? are unknown. For most of us, life operates under a simple equation of winning and losing, my challenges have given me a penchant for suspense. Disease doesn't discriminate—it may cripple a strong person with a wonderful attitude, while it may spare a weaker person resigned to failure. What is stronger, fear or hope? Initially, I was fearful and without hope but I was motivated into taking control by fear. As I sat and absorbed the full extent of my challenges, I refused to let fear blot out hope. Something told me that fear should never rule the heart, and I decided not to be afraid. There is no accurate way to estimate somebody's chances, and we shouldn't even try, it deprives us of hope, the only antidote to fear!

Belief is the bravest human characteristic. To believe in yourself, in the doctors, in the treatment, in the outcome of your endeavors is the most important thing. Without belief, we would be left with sense of doom and the tsunami will overwhelm us! I believe in belief; I believe that I am on the right track, headed in the right direction; I believe that my weekly interferon shots are protecting my liver ; and while on therapy I have a chance to get cured; I believe my regimented routine, my diet and lifestyle choices are protecting my heart arteries from clogging; I believe my spiritual practice makes me take on challenges fearlessly without worrying about the future; and above all; I believe that I am benefiting from my journey... any which way I look at it.

Anything's possible; your reports can tell you that you have a 90 percent chance or a 10 percent chance or a 1 percent chance, but you have to make every effort and believe that you will be in the successful group. What if I lose? What if I am diagnosed with hepatic cancer tomorrow or have a heart attack? In the bargain, I still would have gained in my endeavors, because during my journey I will become more complete, more compassionate, intelligent and therefore more alive.

The one thing my medical challenges have convinced me — more than any experience I've had is that “we are much better than we know, we all have capabilities that emerge in extreme situations, so if there is purpose to the experience of embracing life it has to be this: “our experiences are meant to improve us.”

A man is caught in a flood, and as the water rises he climbs to the roof of his house and waits to be rescued. A guy in a motorboat comes by, and he says, “Hop in, I'll save you.” “No thanks,” the man on the rooftop says. “My Lord will save me.” But the floodwaters keep rising. A few minutes later, a rescue plane flies overhead and the pilot drops a line. “No, thanks,” the man on the rooftop says. “My Lord will

save me.” But the floodwaters rise ever higher, and finally, they overflow the roof and the man drowns. When he gets to heaven, he confronts God. “My Lord, why didn’t you save me?” he implores. “You idiot,” God says “I sent you a boat you didn’t respond, I sent you a plane, you didn’t take that either.”

We are all like the guy on the rooftop. Things take place, there is a confluence of events and circumstances, and we can’t always know their purpose, but we can take ownership for our life events and be courageous. We all cope differently in life threatening challenges. Some ignore them, some deny them, some pray, while some numb themselves with intoxicants. Though we may be tempted by any of the above, I think it better that we take our challenges head-on armed with courage and hope for the most favorable outcome.

Pain is temporary. It may last a minute, or an hour, or a day, or a year, but eventually it will subside and something else will take its place. If you give up today the pain of giving up will last forever. So when I feel like surrendering or deviating from my efforts I ask myself, what would I rather live with? The answer gets me back on track with zest!

I write my story to address all the issues I deal with; coping with the unknowns but with a thorough knowledge of the disease, a 100% effort on my part, the patient’s role in cure, and above all, the idea that HCV & Heart disease are not death sentences. It could be a route to an inner life, a better & re-prioritized life in line with our true self. Earlier, I would spend too much time working towards future goals and I became oblivious of the present; now I know that the act of taking care of the present will qualify me for a better chance of a healthier future! My journey has taught me many valuable things about medicine, my overall health, my view of life, and my spiritual development. Of course, I will never know for sure, but I believe I will live a happier, contented & fuller life. If you look for the good in every experience; however bad a situation may appear at first; there is always something to be gained.

Sharing is beneficial for us because it helps us come together and support one another. The crux of my sharing with you is not about disease but about taking control over challenges that life brings; it is about doing your best in situations that might be life threatening. It is about conditioning the mind, adopting a firm resolution and following it up with determined action each day. It is about optimism, discipline, attitude and keeping your chin up in times of adversity. It is about working on deep ingrained paradigms and a belief that the human body is resilient with an incredible capacity to heal & and the mind is the power to drive it. Above all it is about living in the present!

I would not want the epitaph on my tomb to read "The sick guy, a victim of liver & heart disease, who had frequent coronary bypass surgeries & liver transplants," but “The one who did his best in every situation.”

I hope that each of you will enjoy your journey, find the positives, and make your experience the best it can be for you and your loved ones.

Good luck and God Bless!!

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“Hope is both the earliest and the most indispensable virtue inherent in the state of being alive. If life is to be sustained hope must remain, even where confidence is wounded, trust impaired.”

–Eric Erikson.

The Present Day – August 2010



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