Wrap Your Rhythm Around My Heart; Lead Me Through the Dance of Life

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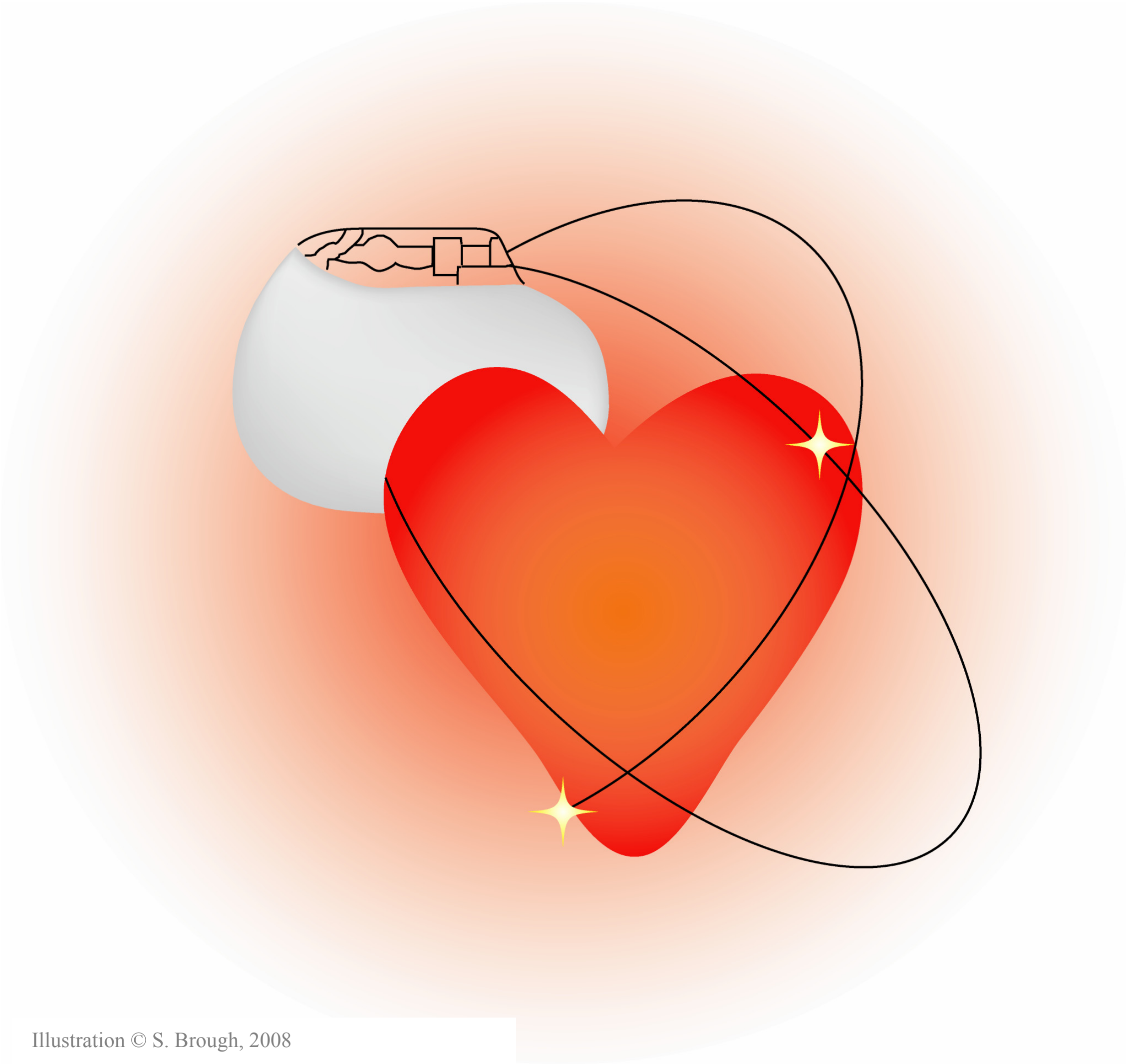

"When a butterfly has to look like a leaf, not only are all the details of a leaf beautifully rendered but markings mimicking grub-bored holes are generously thrown in. "Natural selection," in the Darwinian sense, could not explain the miraculous coincidence of imitative aspect and imitative behavior, nor could one appeal to the theory of "struggle for life" when a protective device was carried to a point of mimetic subtlety, exuberance, and luxury far in excess of a predator's power of appreciation. I discovered in nature the non-utilitarian delights that I sought in art. Both were a form of magic, both were a game of intricate enchantment and deception." (Nabokov, 1966, p. 425).

When we watch a butterfly float across the sky, we observe the rhythm of its wings and see the extraordinary orchestration of effort to propel itself forward. Likewise, the human heart's electrical conduction system is a miraculous symphony of survival. This symphony produces a natural rhythm, a rhythm that we might not always be conscious of, but is palpable in all of our activities. When this rhythm is disrupted, everything in our lives comes to a halt, like a conductor putting his arms down in the middle of a musical piece, the instrument players are then lost without their visual rhythm leader. With the development of pacemakers and implantable cardioverter-defibrillators (ICDs), we can introduce technology into the body that coaxes our hearts into functioning once again. These devices can be the protective dance partner that saves someone from death so that they can continue on in the enchanting dance of life, or this technology can also be a sort of deception since the rhythm it produces is really a false one, and works to tie the patient to a sometimes unwanted dance partner for the rest of their days.

When a person experiences a cardiac event, such as a ventricular tachycardia (the uncontrolled beating of the ventricles), that disrupts their rhythm, a terror washes over them. This terror does not only come from the pain the patient is experiencing from a lack of oxygen reaching their organs, but also the familiar rhythm on which they have been reliant all of their lives is now gone. Without it, the feeling of a trap door opening underneath for a fall into strange territory emerges. Everything that was familiar now becomes foreign and uncertain. Many of those that are lucky enough to survive are introduced to a life-saving and yet, life-altering technology.

Many diseases and disorders can interrupt the heart's conduction system, for which implantable cardiac pacemakers and ICDs are some of the most powerful tools used to restore and maintain proper rhythm. Technologies for each of these devices are rapidly advancing, and implant rates on both types of devices have continuously risen since their development. While pacemakers are proven to assist in the treatment of bradycardia and some tachycardia conditions, implantable cardioverter-defibrillators have been developed not only to treat the traditional tachycardia and possible fatal arrhythmias, but have been enhanced to pace the heart as well. This enhancement, combined with the expanded reimbursement payment over the traditional pacemaker, has caused a dramatic increase in implant rates for both bradycardia and tachycardia patients. This increase is alarming as ICD treatment can prove to be only marginally effective in some conditions, and in certain segments of the patient population, can cause serious side effects and quality of life issues. Given these conditions, we must ask if there exists an overuse of ICDs in adults in America by the medical community in two-thousand-eight, motivated by both the increased profitability of implanting these devices over that of the traditional pacemaker, and as a safeguard against malpractice cases, or whether a different approach to these devices that considers both the mental and physical well-being of patients would be more beneficial.

The Basics of Conduction

Like a conductor taking the stage at the beginning of a concert, the sino-atrial (SA) node takes the lead in the process of depolarization. The SA node taps out an electrical impulse that causes the atria to contract. This is the beginning of a heart beat. Just as the melody in a musical score can be organized to start in the violin section and flow to the violas and cellos, so does the electrical charge through the heart. As the atria contract filling the ventricles with blood, the

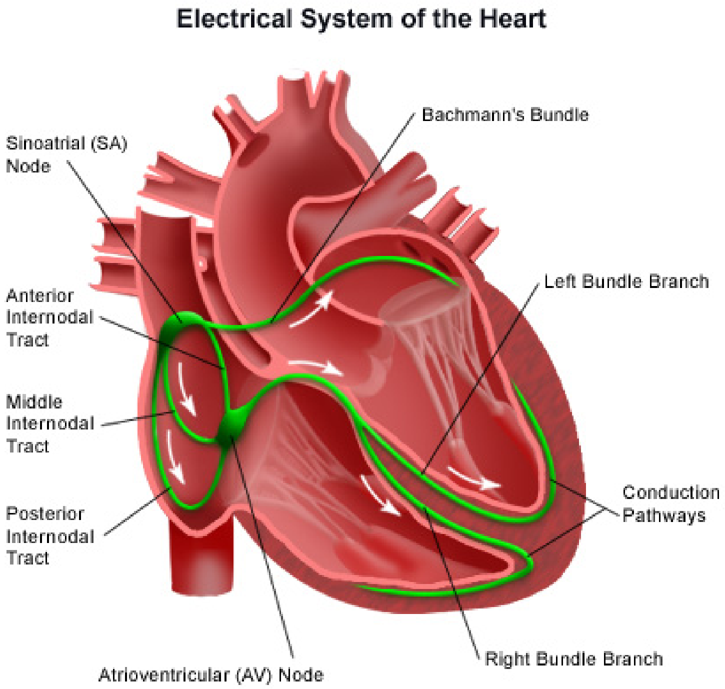

Image courtesy of University Health Care
http://healthcare.utah.edu/healthinfo/pediatric/cardiac/afes.htm

atrioventricular (AV) node will then pick up this current, and pass the charge down the His Bundle. This sends the charge to the left and right bundle branches and finally, to the Perkinje fibers, causing the ventricles to contract and pump blood out to the body (Dubin, 1996).

Interruptions in this process can cause conditions that can be categorized into two types: bradycardia and tachycardia. Both of these conditions are measured from a patient's resting heart rate—the number of heart beats per minute when the body is at rest. According to the Mayo Clinic's website (2007a, 2007b), bradycardia can be defined as a heart rate of less than sixty beats per minute while at rest, whereas tachycardia is a resting heart rate of over one hundred beats per minute. In either situation, the patient's body is not receiving a sufficient blood supply and could experience symptoms such as dizziness, fainting and fatigue and if a regular rhythm is not restored, a life threatening arrhythmia can possibly develop. Arrhythmias are classified as any abnormality in the heart's natural sequence, with the most dangerous arrhythmias being ones that occur in the ventricles for a sustained period of time as this can cause them to quiver and halt their ability to pump blood out to the body. Pacemakers are traditionally used to treat patients that experience bradycardia related complications and some tachycardia conditions, and ICDs for tachycardia patients when antiarrhythmic drugs fail to correct the problem.

Device Overview

Cardiac pacemakers and ICDs are implanted and connected to the heart in a similar fashion. Both are small, oblong titanium enclosed electronics implanted in the patient's pectoral muscle connected to a set of lead wires that attach to the heart's surface (Ellenbogen, p. 196). The devices have the ability to monitor the heart's rhythm, and in instances when the patient's heart is not able to coordinate the electrical conduction properly, transmit an electrical pulse, sometimes referred to as a pacer spike, to the heart through the leads which causes it to contract. This is known as cardiac pacing. ICDs can perform this pacing and also have the ability to monitor the heart for rhythm that is too fast, and deliver a powerful electrical pulse,

Photograph of an ICD
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usually about seven hundred volts or twelve joules, to the heart to attempt to break it out of that rhythm pattern and return to a normal sinus rhythm (Brunn, p.2). When an ICD is required to act on an arrhythmia, the resulting shock can be painful to the patient, and requires them to seek medical help immediately to undergo observation and perhaps an electrophysiology study to ensure that their rhythm has returned to normal and cardiac arrest is not likely to occur.

Device life is an issue for most patients. The average battery life of a pacemaker or ICD is approximately six years, although this battery life can be widely variable depending on the patient's dependency for pacing or frequency of defibrillation shocks (Ellenbogen, p. 380). Some patients require little pacing from their pacemaker and some ICD patients never require a shock from their ICD. In contrast, other patients are completely dependent on their pacemakers for every heart beat, and some ICD patients receive frequent shocks. Weighing in the average patient experience of these devices, most will probably obtain the average of six years battery life. Once the battery enters its end of life parameters, the patient must undergo another surgery to remove the old device and insert a new one. Some refer to this as a battery change; however, neither a pacemaker nor an ICD's titanium shell can be opened such that the entire generator needs to be replaced.

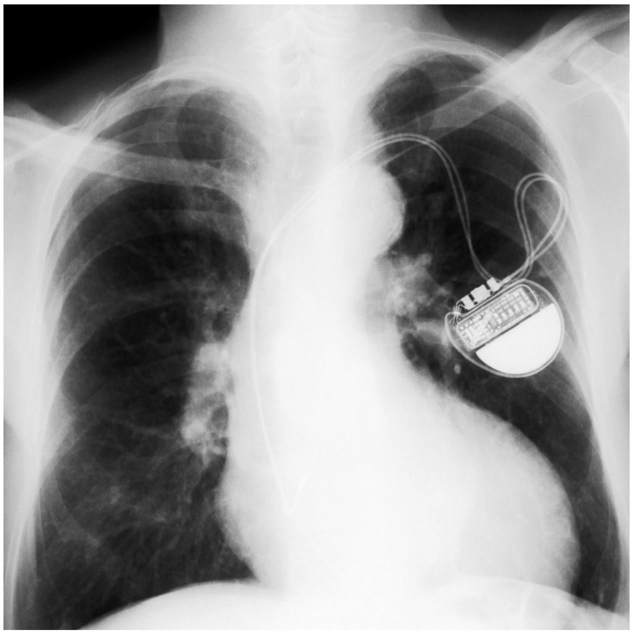
Quality of Life Issues

As Emerson (1836) wrote, "nature never became a toy to a wise spirit," the introduction of technology into the body can help one condition while having a negative effect on many other aspects (p. 143). To not understand this concept is to treat nature as a toy, and act in a manner that is too simplistic and ignore the fact that a patient is more than just a single ailment that can be cured with a mechanical object, but rather a myriad of interdependencies. A clinical study, conducted by the National Institutes of Health determined that survival rates for heart failure patients that received an ICD in combination with antiarrhythmic drug therapy, have a survival rate that is approximately seven percent higher than patients treated with drugs alone (Bardy et al., 2005). The response to this finding has been increased reimbursements by health insurers for the devices, associated surgeries, and post-operative care (Meier, 2005). As a result, ICD usage has increased from just over fifty thousand implants in the year two thousand to well over one hundred and sixty thousand in two thousand six (Hammil et al., 2007). While the claim of the study may lead to the true conclusion that survival rates may be slightly increased with the use of an ICD, it does not take into account the quality of life issues that accompany the surgery, stress, and potential shocks that the patient must manage.

ICD surgery is typically referred to as anything from minimally invasive to the Mayo Clinic's (2006) website description of it as "minor". The patient is given a local anesthetic to help them relax, and some patients may even fall asleep during the procedure. The surgeon will make an incision in the pectoral muscle and guide the lead wires down to the heart through a vein. Once the leads are in place, the surgeon will make a pocket in the pectoral muscle for the generator, and connect the device to the leads. During this phase of the surgery, the patient will be medically coaxed into an arrhythmia to ensure the ICD will react and deliver the expected shock. This will take place while the patient is conscious, but sedated (Intellihealth, 2006). This testing is not only painful for the patient, but according to Pires (2007), proves to be only marginally effective at predicting the device's capability of stopping a spontaneous arrhythmia.

Once the testing is finished, the surgeon will close the incision site. ICD implantation surgery is completed in approximately one to three hours.

Although less than one percent of implant patients die as a result of the procedure, complications can arise, and it is estimated that twenty-five percent of ICD patients will incur some type of problem (Alter, Waldhans, Plachta, Moosdorf & Grimm, 2005). Infection at the implant site, bleeding, damage to the heart muscle or lung should one of the leads dislodge and cause a tear, stroke, cardiac arrest, and life-threatening blood clots are among the most serious possibilities. After the surgery, the incision site will be swollen and tender to the touch for a few weeks. Nonaspirin pain relievers are usually sufficient in controlling the discomfort patients feel. Range of motion with the left arm will be limited at first because of the soreness after surgery. Due to the fact that the surgery is so straightforward and the post-surgical pain easily controlled, it may seem to patients and healthcare providers that the procedure was trivial. This thinking can lead patients to dismiss the importance of attending cardiac rehabilitation, and healthcare providers to overlook the importance of prescribing it.


X-Ray of an Implanted ICD and Leads
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Most patients are discharged from the hospital within one day of the implant surgery; however, the post-surgical restrictions can impose significant lifestyle changes. Following the implant and release from the hospital, the current standard of care is to provide the patient with a brief brochure outlining post-operative incision site care and activity restrictions and schedule their follow-up appointment. See Appendix A of the Vanderbilt University Medical Center's ICD Implantation Home Care Instructions for an example of this instruction.

In the first six weeks following the implant, patients are limited from lifting anything over five pounds, raising their arms above shoulder height, playing sports, and participating in any kind of strenuous sport or activity. These limitations could impair parents from lifting their young children, athletes from playing their favorite activity, and workers from returning to their jobs should it require any heavy lifting or arm raising. Restrictions of this nature vary from patient to patient, depending on their level of conditioning before the surgery. Patients that are very fit and strong may recover faster and regain strength and movement in their arms sooner than patients that are more deconditioned. A very deconditioned patient may need to attend a rehabilitation program to regain strength and proper range of motion for weeks before they can comfortably move past these restrictions. More imposing though is the American Heart Association's (1996) guidelines for arrhythmia patients that would prevent syncopal (fainting) patients from driving for six months following the implant at times, and should the device ever need to discharge a shock, another six month period of being forbidden to drive would ensue to see if the patient displays any symptoms of fainting.

Monthly or bi-monthly remote follow-up testing is performed on the patient from their home that will asses the status of the heart's interaction with the device, ensure that the leads are intact and functioning properly, and check the battery life remaining in the device. Patients must also visit the cardiologist's office on an annual or semi-annual basis to undergo device interrogation and if required, a reprogramming of the device parameters, but beyond that, most patients are instructed to return to their normal life with no assistance in transitioning to living with their new device.

Have you:
- Had a heart attack?
- Been diagnosed with heart failure?
- Had some heart rhythm disorders?

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Medtronic "What's Inside" Website Ad
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The cost of an ICD is upwards of forty thousand dollars, whereas the cost of a pacemaker is approximately eight thousand (Sholder, 2008). As the same companies that manufacture pacemakers also manufacture ICDs, it is much more profitable for them to promote the ICD. The most notable of these campaigns is from the pacemaker and ICD market leader, Medtronic. Medtronic launched the "What's Inside" campaign in two-thousand-seven, as pictured above, and for the first time in pacemaker or ICD history, was allowed to market their devices direct to consumers. This multi-million dollar campaign contains images of happy sudden cardiac death patients enjoying the sweetest moments of life: kissing babies, talking walks in the snow, holding hands with their spouse, etc., all made possible by their life-saving technology. Most of all, it promises ICD candidates peace of mind. This sends heart failure patients the message that the ICD is superior therapy to the pacemaker because of its capabilities, but fails to explain the negative impacts an ICD can have on patients, or explain that not all rhythm disorder patients are at a significant risk of sudden cardiac death. As physicians are now receiving pressure from the manufacturers to use ICDs over pacemakers, and pressure from their patients seeking the promise of a protected life, ICD use is rising rapidly.

Proponents of the increased use of ICDs point to the fact that the use of pacemakers carries with the implant some of the same risks and complications and aftercare procedure. Comparable to the sensation ICD patients feel of their device pulsing when reacting to bradycardia, pacer patients will feel the same sensation. The difference in this situation is that the pacer patient will feel it more continuously, and grow used to the feeling. Some patients even find it comforting since they equate it to a feeling of security that their heart is beating. ICD patients typically are being treated for tachycardia, and thus, the pacing pulses will be much rarer since it is a response to bradycardia, and the unusual feeling will cause them anxiety over wondering if their heart is starting to fail. The risks of infection, lead tears, and clotting also exist, however, pacer patients do not need to undergo the painful process of induced shocks that ICD patients do. In addition, there exists a condition that is unique to pacer patients over ICD patients called pacemaker syndrome. In this condition, the heart can lose synchrony between the atria and the ventricles, and is only associated with right ventricular pacing. This syndrome is usually not life threatening, but can lead to headaches, dizziness, and tiredness in patients. The response to patients that experience this condition is to use a bipolar pacemaker and reprogram their device to ensure that the pacing is atrial based (Farmer, Estes and Link, 2004). This serves to correct the problem in most cases. Pacemaker patients do not experience the same stress response to living with their device as do ICD patients as there is no threat of defibrillation shocks. Many pacemaker patients have the device to prevent a worsening of their condition instead of living with the uncertainty of being reliant on the device for saving them as do ICD patients (Sholder, 2008).

In an effort to better understand differing views of possible device overuse, I turned to an industry expert. The pacing industry is probably not one most people would think of as exciting or having as aspect of glamour to it. Those who operate under that impression have not had occasion to walk around a scientific session exhibit floor, such as the Heart Rhythm Society, with Jason Sholder, Ph.D. Having held many high-level positions within the industry, Senior Vice President of Technology at Pacesetter, Inc., which eventually evolved into St. Jude Medical, Inc., President and CEO of Raytel Cardiac Services, Inc., the nation's largest provider of transtelephonic follow-up, and COO of Impulse Dynamics, and the inventor of The Clapper, Jason is not only one of the most interesting people I know, but one of the most recognizable people in the pacing world. Walking an exhibit floor with him is like walking through a shopping mall with a rock star. People know and like him, and most of all, have a great respect for his technical expertise and outstanding creative ideas that led to many innovations in cardiac pacemakers.

I started out by approaching the topic of device overuse with Jason and was soon embroiled deep into a topic that he is quite passionate about. In Jason's opinion, neither pacemakers nor ICDs are really overused. He says the medical community views both pacemakers and ICDs as they do chicken soup, in that they can not hurt. He thinks that the general public has formed the opinion that pacemakers are overused because of their rate adaptive capabilities. Since a pacemaker can monitor the heart's function and deliver a pacing pulse only when necessary, it is possible that some patients are paced infrequently, even only two percent of the time. This might cause people to think their device was implanted unnecessarily, but as Jason explains, if a patient has a documented syncopal (fainting) episode, the origins might be unknown. This would mean that it might be impossible to tell if it is a permanent or transient condition. Further, heart block is usually progressive so that if an episode was caused by a first degree heart block and is left untreated, second or even third degree heart block will usually develop. If the block is treated with a pacemaker, this minimizes the chances of it worsening as the heart will be paced when needed, and further damage to the heart avoided. Jason also points out that a treated heart block will allow patients to carry on their previous activities. For example, a cardiac syncopal episode would prevent an airline pilot from being able to fly, however, if treated with a pacemaker, the pilot would then be able to pass they physical exam and be cleared to continue his work.

When the subject turns to ICD overuse, Jason has similar feelings in most conditions. If a patient has already experienced a tachycardia or fibrillation episode, his opinion is that ICDs are minimally invasive and can protect the patient and those around them from further harm since it is possible the next episode the patient has could be while they are driving or performing another activity that could become dangerous should the patient lose consciousness due to their heart condition. If a patient is then able to be provoked into a fibrillation or tachycardia episode in an electrophysiology study, then he feels that the patient should receive a standard ICD. If the patient is experiencing heart failure, such as wide QRS complexes that are indicative of many conditions such as a bundle branch block, then the patient should receive a bi-ventricular pacing capable ICD. The only exception to Jason's feeling that devices are underused is in those conditions where the patient presents a heart condition of narrow QRS heart failure. Here he feels that the devices are being implanted with no chance for improving the condition. What narrow QRS complexes means is that the heart is losing left ventricle synchrony, and there exists no clinical evidence that an ICD will cure or improve the heart failure in these patients.

Jason's background is so diverse that he has both a clinical and engineering perspective on this issue. I disagree with the thinking that these devices follow the chicken soup philosophy. As we will see, there is a negative impact on the patient in living with one of these devices. If they are being implanted in patients for which there will be no real utility, as those with narrow QRS disorders, which according to John F. Beshai, M.D., comprises approximately one hundred twenty-five thousand heart failure patients annually, then there is a serious situation of overuse with ICDs (Peck, 2007). If narrow QRS disorders affect a quarter of heart failure patients, and this ratio is reflected in the implant rate, this would mean that there are approximately forty thousand patients per year living with an ICD and most likely not receiving any benefit while enduring the negative impacts of having one.

As the expansion of coverage for ICDs is promoting their increased use, this wider use of the technology means that the risk of an unnecessary surgery increases, either for a condition it does not really improve such as a narrow QRS disorder, and the unnecessary risks of surgery complications like heart tears, infections and even death. After the patient overcomes those obstacles, they then face the restrictive post-operative period. As if this were not complicated enough for people experiencing heart failure, it does not take into account what they experience after the post-operative period trying to blend their old life with the new reality of their embedded rhythm keeper.

One of the most stressful aspects of living with an ICD becomes the defibrillation shock. Receiving an ICD delivered shock is stressful on the patient. Research by Gehi, Meta, and Gomes (2006) reports that:

> "In a substudy of the Coronary Artery Bypass Graft Patch (CABG Patch) trial, Namerow et al.[6] measured QOL in 490 patients, half of whom were randomly assigned to receive an ICD. At follow-up, patients in the ICD group who received ICD shocks reported feeling less healthy, had reduced physical and emotional role functioning, and had lower levels of psychological well-being." (p. 2840).

ICD patient Deborah Daw Heffernan describes the relationship of her mind, body and the device as a double edged sword. She felt it was reassuring in one respect to know she has a life-saving device within her, but that the ICD also served as a constant reminder that her body could fail at any moment when struggling with issues from being able to feel the device and its pulsing while she sleeps to interaction with other devices that could cause an inappropriate discharge, such as airport security scanners (Heffernan, 2002). Adding further stress on ICD patients is the need to seek medical help after a shock is delivered. The patient at the time does not know if the ICD acted correctly to prevent a life threatening rhythm or not. Only after seeking treatment will they find the results, and since it was found in the MADIT II study that over thirty percent of ICD shocks are inappropriate, they may find that their pain and anxiety were needless (Daubert et al., 2007).

"I tend to be more wary of what I'm doing. I think 'Oh, I think this is going to set it off'…so I don't do it."

> -Clinical study patient survey response to living with an ICD (Tagney, James & Albarran, p. 198).

Imagine that you are a runner in a race on a hot summer day, but in this race you are lost from the course, and someone is chasing you. You really want to give up because you are exhausted from the heat, completely and utterly disoriented as to which way to go, and very discouraged. In doing so though, you will never cross the finish line reuniting you with your friends and family to celebrate your victory. Worse yet, this person that is chasing you gets to shock you with a cattle prod if they catch you so stopping to figure out where you are and where you should head to finish the race is impossible. You have no choices in this situation, if you give up you face the pain of a shock and if you keep going on lost you could just be moving further and further from your goal.

This is the ordeal many ICD patients face concerning rehabilitation after their implant, a sort of vicious cycle for which there does not exist a lot of research or evidence to help them break away from. If we understand the heart to be a muscle, then our instincts tell us to exercise it so it will get stronger. We relate this to our use of our biceps in which if we perform the proper weight lifting exercises, our biceps will get stronger, bigger, and have an increased capacity to do work for us. While this is true for most muscles, the heart of an ICD patient comes with a catch. Work out too hard or improperly, and you could face the pain of an inappropriate shock. An ICD is programmed to administer aid if it senses a heart rate, usually about one hundred and twenty beats per minute, a level easily reached during exercise, along with a morphology that would indicate a tachycardia arrhythmia. As humans, we like to avoid pain, like an ICD shock, whenever possible, so it starts to seem that exercising is not a good idea. Avoid working out and avoid the potential shock. Many ICD patients follow this mentality.

Now the patient is in the grips of the cycle. By avoiding exercise, they believe they are avoiding a shock, but now they are getting weaker. The weaker their body gets, including their heart, the harder everyday tasks such as bringing in groceries from the car or climbing stairs, will become. Eventually, the strain of these tasks becomes so great, a life threatening arrhythmia develops and the ICD is needed to act, although the weaker the heart, the less effective the ICD becomes at being able to restore the heart back to a normal sinus rhythm. The ICD will then be administering shocks at a greater number of joules so the pain is worse as well. At this point the patient has not really avoided the pain they had hoped to by not exercising. They have only slightly managed to prolong the time before they felt a shock, and have worsened their condition to the point that the shock(s) might not be able to save them. What is needed for these patients is a sort of race guide. Someone who can tell them how to live with their device, and stay on the course so that they run down the path of getting stronger, while not triggering their device. That course guide needs to help them mentally and physically.

Lack of Support for ICD Patients

Once a patient receives their ICD, they are given the list of restrictions during the healing time that were discussed earlier, and then told to go on and live life as normal. Some may be sent to an exercise rehabilitation program, but most are not. This nebulous instruction and lack of support can lead to an increase in Hospitalization Anger and Depression (HAD) scores that measure the anxiety patients are feeling. For many ICD patients that received their device as a result of cardiac arrest or sudden onset of symptoms, a study led by Kataneh Maleki, M.D. reports that ten percent may even experience what is known as a “phantom shock,” in which a patient seeks treatment because they believe their device has delivered a shock when it has not been called on to do so (Wood, 2002). The anxiety ICD patients are feeling combined with a lack of support can lead to the manifestation of symptoms that did not actually occur, or even worse, not prepare patients properly for what can occur when their device reacts to an arrhythmia.

For one patient, J.B., the instruction to just go back to his normal life almost led him become disabled by his ICD. J.B. (2008) describes his device as both a life saver and a near “lifetaker.” While trying to get some exercise just a few months after implant, J.B. was riding his bicycle in July two-thousand-five, as was his usual pattern before the surgery. During the ride, his heart went into an arrhythmia and the device intervened to deliver a shock. J.B.’s doctor had only told him that when an ICD needed to deliver a shock, it would just feel like a small thump in his chest. Completely unprepared for the reality of an ICD shock, J.B. was outside riding on a bicycle and the pain and jarring from a thirteen-hundred volt shock caused him to fall over and sustain a brain injury that caused him to remain in a coma for over a month, and unable to return to work. His physician should have advised him of the possibility that he could lose consciousness during an arrhythmia or defibrillation shock, taken into account the patient's active lifestyle, and instructed him to ride a stationary bicycle. For reference, the typical shock from an ICD is about seven-hundred volts. Household electricity runs on one-hundred twenty volts or two-hundred twenty volts, and an electrician might work with commercial level voltage up to four-hundred eighty volts. The shock J.B.'s device delivered was much too high and most likely the result of improper programming at the time of implant. He ended up on Social Security Disability, and must now take anti-depressants and anti-anxiety medications. Stories like these are all too commonplace, and J.B.'s opinion is that if his physician had advised him of the proper precautions and a support group was available at the hospital where he received his device, that his suffering could have been avoided. He is currently in litigation over the matter against his physician, and hopes that this will call attention to the issue of properly warning patients. As a patient's life is irreversibly altered after receiving an ICD, more must be done to support and advise them through the transition.

Hospital support groups, such as "The Beat Goes On" based out of St. Peter's Hospital in Albany, New York, meet quarterly to discuss device related issues such as device recalls, cardiac disease, and lifestyle changes. They estimate approximately twenty to forty people attend these meetings on a regular basis (EP Lab Digest, 2007). For a major medical center like St. Peter's Hospital, twenty to forty people attending this group represents a small fraction of their ICD patient population, which means that the majority of their patients are not benefiting from this kind of support. Fifteen to sixty percent of ICD patients will experience some type of anxiety problem as a result of receiving the device (Edelman, Lemon, & Kidman, 2003). As such a high percentage of ICD patients are experiencing anxiety problems, we know that there is a need to address this issue.

> "It is remarkable how a sense of valediction heightens one's awareness of the beauty of the world. I think it is because beauty is a summons to a journey, is both a hail and farewell of the spirit, and since our deepest pattern is a round of departure and return, we never recognize it more clearly than at the beginning and end of our journeys." (Van Der Post, 1961, p. 470).

In performing patient interviews, Van Der Post's (1961) words about true appreciation of life and our environment resonate in that, "we never recognize it more clearly than at the beginning and end of our journeys." (p. 470). Each person with whom I spoke had come close to the end of their voyage in life, and come back altered. For two patients, A.R. and E.H., a sense of humor, appreciation for life, and recognizing the need for a strong social network served to stoke the fires within that has them seeing the device as worth more than the trouble it might cause to them, and working to help others overcome the changes an ICD brings about. For patient, J.B., determination to rectify the industry wide failure to warn patients fuels him on to warn others of potential dangers. In each case, ICDs have left each person wanting to help others on their path to a healthy lifestyle that the current practices in the medical community fail to provide.

Patient E.H. was a fifty-two year old woman at the time of her implant that was energetic—putting in fifty to seventy hour work weeks. Her bradycardia, left Bundle Branch Block, cardiomyopathy, and valve regurgitation left her with a left ventricle ejection faction rate of less than ten percent and put her at serious risk for Sudden Cardiac Death (SCD). Receiving a Medtronic ICD, E.H. was left after the surgery nervous the device would fire, and no aftercare program such as cardiac rehabilitation, relaxation guidance, peer support group, or nutrition counseling. The anxiety at first caused some hesitation in resuming some activities, but E.H. (2008) found comfort in humor with her family and eventually developed what she calls a "bionic woman syndrome" in thinking that the device will actually not allow her to die. The comfort of humor and the thinking that the ICD provides a safeguard against death were necessary tools that E.H. used to cope with her first shock.

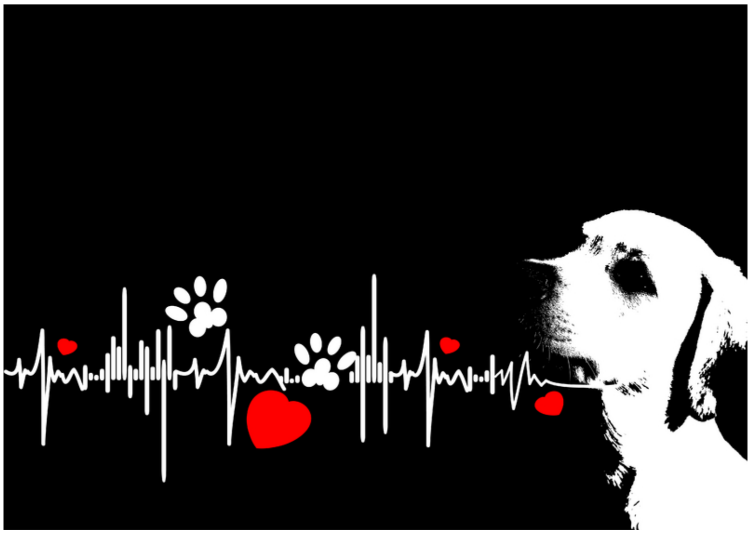
When her device was needed to deliver therapy, E.H. had actually thought she had been electrocuted. Like J.B. and other patients, she was told a defibrillation shock would feel like a thump in the chest. As she was in the shower at the time touching the faucet handle, E.H. describes the shock as having such force it caused her to "see white." Once the shock was over she relays that there was no pain afterwards, and is grateful for the intervention. In another arrhythmic episode, E.H. sought medical assistance from the fire department across the street. After a very brief consultation, they sent her home but E.H. had a feeling that things were just not right and went to the emergency room of her local hospital. There she was told her heart failure condition had worsened. Still without any support, E.H. turned to the Internet to find answers about when she was going to die.

Instead of finding a timeline to her death, E.H. found a support group called ZapList through a post on the American Heart Association's message board. There E.H. connected with others that have an ICD, and share moral support on issues concerning living with their device and heart failure. In retrospect, E.H. wished that there had been an in-person support group available in her area at the time of implant. She feels that she has benefited from the shared knowledge and support from the Internet group to the point that she was encouraged to ask more questions at her last ICD interrogation and get definitive answers. She looks at the necessity of support groups being provided by hospitals as it "being their [physicians] jobs, but our lives. The support group gets you involved in how you are going to live." As she grew more involved in her care, E.H. has spread her humorous and empowered attitude on to even her grandchildren, one of which jokes that she wants her grandmother's ICD explanted and given to her should E.H. expire.

Ironically, technology brought E.H. support, but it might also work to take it away. At her last interrogation, she was enrolled in the Medtronic CareLink program. CareLink is a remote monitoring program for ICD patients in which the clinicians can obtain the interrogation data from the patient's device using a monitor that sends the data over phone lines, and makes it available for review from a secured website. E.H. was disappointed with this as she feels that she will have less interaction with her medical staff, and get fewer answers to set her mind at ease. This need for answers and support has caused her to consider initiating a support group in the Orlando, Florida area.

The calling to offer others the support they so very much needed when they received their device also affected patient A.R. A forty-three year old man self-described as a "Type A personality", A.R. (2008) suffered a heart attack in 2004. He received his first of four ICDs, a St. Jude Medical unit, but his condition included problems of atrial fibrillation, ischemic cardiomyopathy, coronary artery disease, and chronic heart failure, which required bypass surgery later that week. Prior to this event, A.R. was an avid athlete and traveled all over the world. The restrictions and changes A.R. faced, such as giving up activities like cycling, caused him to experience a period of depression. The loss of control he felt caused him to stop taking the medications he required to treat his conditions. He felt that he wanted life to operate on his terms once again even if it meant worsening his heart failure. Fortunately, he had a group of friends that encouraged him to go on, and while he did attend therapy for his depression, he found more answers in the lifestyle changes he needed to make. A diet overhaul and exercise program were incorporated into his life, and also A.R. finds strength in discussing his condition with a close friend, another man about the same age that has an ICD, and like A.R., was an active individual prior to his heart problems. Additionally, A.R. attributes the charismatic and positive attitude he projects in part to adding his dog, Buddy, to his life.

The motivation Buddy brings to A.R.'s life is both physical and psychological. Buddy requires frequent walking that helps his owner stay active, and gives him a reason to stay well. The emotional attachment was strongly perceived during our interview as A.R. spoke much more excitedly when the conversation turned to Buddy. He finds that he wants to do whatever it takes to stay out of hospitals not only because he wants to prolong his life, but so he can enjoy spending more time with his dog. A.R. believes in the benefits of this kind of emotional support so much that he is trying to coordinate a program with his local American Heart Association chapter and the Humane Society to match homeless animals to cardiac patients. Further supporting the benefits of this type of social support are the results of the CAST study in which it was found that the one-year survival rates of acute myocardial infarction sufferers were much higher among dog owners than patients that did not own pets. (Friedmann & Thomas, 1995).



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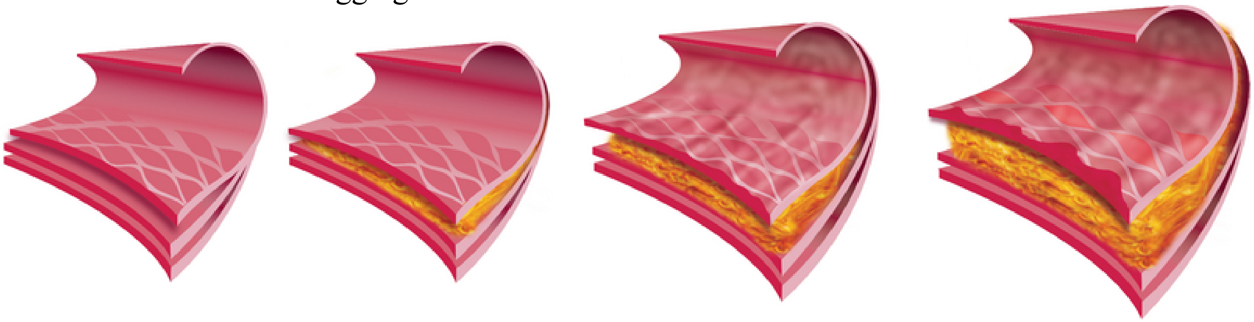
The support A.R. found was necessary in dealing with his health issues. With his original ICD, A.R. had a lead fracture, which was attributed to the repetitive motion from his swimming, that led to an inappropriate shock. As others stated, the force of the shock was so overwhelming to A.R. that it literally knocked him out of his desk chair. When I asked him to describe it to me, he framed the incident with the reference that he had been through many frightening things, like a helicopter crash, and the ICD shock was much scarier. He also would not be able to sleep for days after he received shocks due to the anxiety of anticipating future shocks. He was so discouraged with his first ICD at that point he considered explant and not getting another. He did eventually decide to proceed with another generator and lead, which were placed to accommodate his active lifestyle. This adjustment did not prevent future problems.

A.R.'s second generator's battery was depleted within a year because of his atrial fibrillation that caused the device to fire frequently, and when replaced with his third St. Jude Medical unit, he suffered such a terrible infection that it too was explanted. At this point he made the decision with his medical staff to try a Medtronic unit, and has had no problems to date. All of these generator and lead problems occurred within a four year period, and amidst his heart failing more severely. I asked A.R. about whether or not he felt having the ICD was worth all the trouble and he laughed that as they had worked to save his life on several occasions, it was completely worth it.

With his ejection faction dipping down to less than fifteen percent, he was at one time referred to the University of Miami to be considered for a heart transplant. As part of the preparation of candidates for transplants, A.R. was required to attend a support group. He found tremendous value in speaking with other people experiencing the same issues that he was, and attributes the availability of such a group to the academic environment versus the commercial environment where he received his original treatment. A.R. was so disappointed in the aftercare he received at the commercial hospital where he first underwent treatment that he considered moving. He had to request a prescription to a cardiac rehabilitation program and seek out nutrition counseling on his own. The cardiac rehabilitation program he was sent to was only covered by his insurer, BlueCross BlueShield, for fifteen hundred dollars per year. This meant he would receive only ten sessions before being sent off to exercise on his own. When speaking with A.R., it is easy to detect that he is not your typical patient that listens to their medical staff and is reserved about questioning them or asking for things. He is extremely self-educated about his condition, and knew that his life depended on proper exercise and nutrition to help him recover. The amazing aspect of his story is though that he was very active and fit before his heart attack that did all this damage to his heart. It was a lack of diagnostic testing during routine physicals, such as a stress test or CT angiogram, that could have notified him and his provider that his heart was in trouble, and intervention could have been done earlier that probably would have him in much better health today. Due to his high level of conditioning before and after his heart attack though, he is eligible to participate in a groundbreaking stem cell trial and hopes to actually completely recover from his heart ailments.

I was able to connect with A.R. through the same ZapList Internet support group that I had contacted E.H. Finding such value in the heart transplant support group he attended at the University of Miami and the ZapList, A.R. also had strong feelings about the necessity of these for other ICD patients, and even expressed an interest in contacting patient E.H. since together they could start groups in two major Floridian cities, Orlando and Miami, which could also be accessible to ICD patients in the Palm Beach area that lies between them. The availability of support groups could have played a critical role in warning patients about the dangers of having an ICD that for patients like J.B., his physicians and device manufacturer failed to provide.

Now that we know of the problems and complications in the medical community for ICD patients, we must also examine the patients themselves. The ICD Registry tracks patient demographics for all ICDs paid for by Medicare, and from that profile, we can put together the picture of the average ICD patient. From the two-thousand-six registry data, the average age of an ICD patient is sixty-eight years, and seventy-four percent of recipients are male with the overwhelming majority, eighty-three percent, being Caucasian. Over sixty-six percent of all ICD recipients had a history of coronary artery disease (CAD), thirty-six percent with diabetes, and seventy-two percent of patients had high blood pressure. (Hammil et al., 2007). As the majority of patients had a history of CAD, which is categorized as an acquired cardiac disease, diabetes and high blood pressure, we can reason that many of those patients had diets that were high in cholesterol and saturated fat which leads to the body's inability to eliminate those from the blood stream and results in a clogging of the arteries.



Progression of Coronary Artery Disease (CAD)
© Larry Almonte, 2008

It is typical, although not definite in every case, that most people suffering with any one or all three of those conditions are overweight. Since the ICD Registry also tells us that nearly one-third of the recipients had had previous surgeries for coronary artery bypass, we know then that following the CABG surgery that their condition did not improve and an ICD was required. The Registry does not say if that was due to lifestyle factors, like failing to change dietary habits or obtain enrollment into an exercise rehabilitation program to improve their CAD (Hammil et al., 2007). Given the American culture is categorized by Alpert, Flinn, and Flinn (2001) as one "that gratifies itself with every conceivable type of food taken in excess alongside of widespread physical inactivity," we know that the patients do contribute in many cases to their condition (p. 10). Take this factor and combine it with the problems we have seen in medicine and insurance, and patients are left without tools to help themselves, and only react to disease with drastic intervention as the need arises.

Many people might look at each of these interviewees and think that they had been given a sort of unfortunate life lottery ticket in that they suffer with heart disease. What defines these patients though is not that they live with this problem, but as Pyle (1986) wrote, each has chosen to use their abilities and sought change to, "live selectively, choosing that which we wish to experience." (p. 974). These patients have many aspects that an ICD patient needs to live well with their device: J.B. and A.R. were and are both physically active people, A.R. built his own support network and made the necessary dietary changes, and E.H. has a support network around her. What is missing is coordination in the healthcare system that takes advantage of motivated patients like these, and gets them all of the tools they need to live the best life possible. Each person I spoke with is grateful for their life, and is working hard to accept the problems they have had to deal with and find a purpose that makes their journey through life with heart disease worthwhile. The common thread between each patient is that they want to spare other patients the pain and suffering that they have endured, and find ways to bring their peers the comforts they have found.

The Heart of American Values

> "I am in the heart of life. But look—there is my body in that looking glass. How solitary, how shrunk, how aged! I am no longer young. I am no longer part of the procession." (Woolf, 1931, p. 193).

It is easy to think of ourselves as singular beings and ignore the truth that we all dance together as a society forming a procession with a wide reaching net. Some of us will age to be ICD patients, some not. Some of us will be the health care providers to those patients, and others will be a part of the industry. The values of these procession dancers have a great impact on the others, and in some cases those values have to be examined.

We've all been at some low point in our lives and told by others to be grateful for our health. Most people will think of this as merely some kind of tired expression, but really, what does it mean to be healthy? The essential component of being in good health boils down to having a high quality of life. Quality of life is a currency of sorts. It buys you freedom and independence. The freedom and independence to be mobile, spend time as you please and need, express feelings of joy, love or even anger through dance or movement, consume what you want and when you want it, and choose your role in society. Freedom and independence are primarily American values, still highly prized in the year two-thousand-eight. Simply put, quality of life leads to enjoyment of life. To lose quality of life is like the bankruptcy of a soul that usually leads to less enjoyment of life, isolation from those important to us either by physical barriers such as being confined to a nursing home or bed, or not being able to independently control how and where we spend our time. With quality of life being so crucial to being able to join the dance of life and feel the most enjoyment possible in our lifespan, we then must ask ourselves why this is not given the greatest of care and focus.

Greed, laziness and instant gratification seem to take a higher precedence to maintaining and building quality of life. As a society, Americans tend to follow the mass marketing to want the easy and fast solution, such as meals and in as much quantity as we can get it, regardless of what the impact is on our health because it takes time to feel those consequences. Some might argue that greed is good, and that it may motivate some to work hard to amass all that they can. The problem is that greed may start out being a motivating factor, but it eventually leads to an inability to resist temptation. This distorts motivation into the justification of overindulgence that can lead to gluttony in the example of food, workaholicism, or unethical practices whether in business or the care of one's own body. We want the fun of today without regard for tomorrow. We want the stocks we buy today to pay off quickly so we can sell them at a profit, not wait years to see our wealth build like previous generations did. We want convection microwaves because our old regular microwaves took thirty seconds too long to heat our food. We want to lower our taxes now so we can spend that money on consumer goods instead of investing in a system that works with us to give us the tools to hang on to our quality of life and longevity. This kind of fevered consumption is driven by the constant barrage of marketing we see everywhere; on billboards, on the radio, in our mail, on our televisions, and right down to the paper cups we drink from. Our marketing then has become like the weeds in Michael Pollan's 1991 essay *Weeds Are Us:*

> "It's hard to imagine the American landscape without St.-John's wort, daisies, dandelions, crabgrass, timothy, clover, pigweed, lamb's-quarters, buttercup, mullein, Queen Anne's lace, plantain, or yarrow, but not one of these species grew here before the Puritans landed. America in fact had few indigenous weeds, for the simple reason that it had little disturbed ground." (p. 1089).

Just like we brought the problem of weeds onto ourselves by disrupting the balance of the pre-Colonial American land, marketing has turned back on us to become a plaque in society, clogging up the arteries with messages of the easy and fast solution. It displaces self-discipline for instant gratification.

With self-discipline, a person has a great deal of control. They can control themselves in the face of temptation, act towards long-term goals, and measure the value of today against tomorrow. Essentially, they can make choices today that will benefit their quality of life in years to come. People need self-discipline to be able to choose the healthy meal over the fast food or the exercise over the television watching. They can be mindful of the long term effects of choices like this, and this can be the true source of motivation. Motivation can not come from greed. As we saw it is only an appearance of motivation. Self-discipline causes us to weigh the consequences of our instant gratification today against the negative effects it can have on us in the future. But somehow we as a society have lost this discipline. We no longer have the ability to wait for anything to pay off as an investment. We only respond to problems when they surface instead of heading them off at the pass. These values of greed, laziness and instant gratification have conditioned us into a reactive health care system instead of a proactive one.

The benign warnings of our health care professionals to eat right, exercise and relax fall on deaf ears because most of us do not know how to do those things because we are not taught self-discipline and lump them all into the category of things that are not enjoyable. It takes time to see the results of exercise so we opt instead to take diet pills or pitch watching our weight altogether lying to ourselves that we are not meant to die in perfect condition and have the dessert that we can enjoy right now. Enjoyment is a funny thing though, as it is one of those concepts that we apply to activities we are usually familiar with or have been conditioned to think is enjoyable. We watch the ads for the Olive Garden restaurants of families eating enormous servings of pasta alfredo together, laughing and having a good time. Naturally, we want that same familiar pleasing experience of togetherness because we all do want to be connected—to be part of the procession, but do we really need the liquid heart attack of alfredo sauce to get it? Would our want really change if we twist the looking glass a bit to see that same family was having the same great time bonding over a responsible meal? The answer is no. We would still want that bonding experience.

Alfredo Sauce
© Melanie Stone, 2008

We all have a need to be part of a group. Maslow (1943) listed in his paper *A Theory of Human Motivation* that the social needs of friendship and intimacy are so crucial that humans need to fill those needs after their physical and safety needs are met. As Abram (1996) wrote,

> "Indeed, the ostensibly "value free" results of our culture's investigations into biology, physics, and chemistry ultimately come to display themselves in the open and uncertain field of every day life, whether embedded in social policies with which we must come to terms or embodied in new technologies with which we all must grapple. Thus, the living world—this ambiguous realm that we experience in anger and joy, in grief and in love—is both the soil in which all our sciences are rooted and the rich humus into which their results ultimately return, whether as nutrients or poisons. Our spontaneous experience of the world, charged with subjective, emotional and intuitive content, remains the vial and dark ground of all our objectivity." (Abram, p. 33-34).

In our personal world, we find psychosocial support in being a part of something whether it is a family, group of friends, a sports club, a workforce, etc. This belonging to the dance of life shapes who we are and how we perceive things around us. This shaping can give us the toolset we need to overcome difficult times because an experience of something can seem very different when we are part of a group versus the same experience when alone. When we are a part of something, we are happy and feel joy to be included. Social support then, becomes a vital need. The problem then becomes that when we are excluded from a group, feelings of isolation and sadness develop. Because of the critical need for support, we must then focus on finding healthy and inclusive groups to maintain or even raise quality of life, and avoid groups that have a clique mentality or become so overwhelming they limit the possibility of belonging to other groups. Given now that positive support is key to quality of life, the images of belonging need to change so that we are not sacrificing health to get it. As in the above example of the Olive Garden ads and changing the images to come together through a healthy meal, we can redefine what we want. This redefinition of enjoyment can shape our actions and other values

If we redefine enjoyment, to change our wants, can we also do this in a way that changes society, healthcare, and industry? If we condition ourselves to want a high quality of life for as much time as we can possibly get, would health care change its values and funding so that we can focus on health maintenance instead of waiting to react to problems with expensive diagnostics and procedures? If so, nutrition counseling, exercise guidance and relaxation and stress management, all things that require self-discipline, would become standard teachings in schools and health care systems such that people would be equipped with the tools to live in a way that is responsible for the care of their quality of life. Further, health care providers could take pride not in becoming the superstars of saving lives, but becoming superstars of preserving an enjoyable life for their patients.

Physicians are some of the most courted professionals by industry. This wooing can cause a conflict between the Hippocratic oath and monetary success. As people and members of society, they too will have dancers in their group that can be prone to greed, laziness to the path to success, and the gratification of feeding their ego with the help of industry partners. While some physicians are still in school they will begin the courting process with industry with free trips to medical conferences, sponsoring of their poster presentations which then leads to more notoriety and helps them to secure more lucrative positions as they enter into practice. Once in practice, the industry caters to them as VIPs at conferences, send in sales representatives to dote on their account as if they were the only practioner in town, and sponsor their clinical studies and trials to continue to build their fame and attract a larger patient base that would generate more revenue. As we know that over forty-thousand patients are receiving ICDs for conditions that will not improve by having the device, we must ask ourselves if this courting process is motivating that overuse at the cost of the patient's quality of life. If physicians were conditioned to respect the possibility of prolonging a great life over just keeping a head count of lives saved despite the negative quality implications, would ICD use then be soaring over the last few years? Under this value system, the physicians would have dedicated more time to helping their patients respect the quality of their own lives and live responsibly so that many cases of heart disease could have been avoided. Industry would have a stake in this that could then result in a benefit to them as well.

Industry has a responsibility to their shareholders. The stocks people buy off of E*Trade today comes with the pressure to pay off tomorrow. Industry then has to perform like some kind of dancing monkey for its shareholders to outpace themselves continuously. If the investors, who are really someday the patients, cardiac or not, would slow down their greed and enjoy building wealth over time, the stress level would be reduced. The marketing pressure on the physicians would slow down, and a proper assessment of patients for devices like ICDs and pacemakers could be more accurately made so patients would not suffer any unnecessary hardship like that of inappropriate ICD therapy or depression from being a cardiac invalid. Right now, medical malpractice suits are too commonplace, so ICDs are implanted as prophylactics to hedge off any potential lawsuit. If greed did not motivate so many lawsuits, then the simplistic approach of device implantation would diminish and possibly be overtaken with a more preventative approach.

The core value to preserve quality of life is often overshadowed by values like greed, laziness, and instant gratification. The problem then is that as an interwoven net society is of patients, physicians and industry, the negative impact to this displaced value set leads to higher medical costs in the end, which means more taxes to people, and a diminished quality of life through unnecessary and preventable disease. The procession then becomes a chaotic mingling of solitary, isolated, sick members instead of a harmonious dance of members feeling that they are in, as Woolf describes, the "heart of life." (p. 193).

Changing the Landscape of Heart Disease

> "From this two-way exchange evolves a shared precision, a shared joy in fluidity of motion, rhythm and cadence not unlike the delight an athlete takes in executing for example, figures on skates, or completing a slalom course on skis or performing intricate high dives. We have, blessedly, an atavistic need to let our bodies speak." (Kumin, 1987, p. 574).

Our bodies have an innate ability to express emotions and needs. We express emotions like joy through dance and pain through slowing down or withdrawing. This need for expression should act as a call for attention, with the attention being to the issue of how to preserve quality of life in a preventative aspect, and further, how to maintain it or improve it in an aftercare setting in the context of pacemaker and ICD patients. The need for improved assessment tools becomes critical in this picture. Also required are ways for people to find the self-discipline to perform the exercise and training our bodies need and find ways to make the mind-body connection. When this is done, the combination of these healthy changes with the proper diet, and incorporating the proper social support around us all work in the prevention and aftercare improvement categories. Further, social changes such as fair Medicare and insurance reimbursements are needed to ensure a high level of quality of care for patients and regulation on billing policies of hospitals and purchasing groups on devices are needed. Coordinating all of these changes and looking to the future of the technology will work to create an environment that is conducive to not only allow more access to these life saving devices should a patient need one, but help many patients avoid heart disease and therefore, a device implant.

Model for Change:

1. Assessment
2. Support
3. Exercise
4. Mind-Body Connection
5. Stress Reduction
6. Dance
7. Nutrition
8. Patient Responsibility
9. Industry Changes
10. Reimbursement Reform
11. Taxation Overhaul
12. Purchasing Controls
13. Future of the Technology

1. Assessment

The first step to solving this problem is a more accurate assessment of patients for device candidacy. The standard electrophysiological testing must be modified not only to see if a patient is inducible for arrhythmias, but to look at the heart's function while not in an arrhythmia as a predictor. This can be done by examining the changes in the amplitude of the T-wave portion of the electrocardiogram down to the microvolt level. This is called microvolt T-wave alternans (MTWA). The reason that this diagnostic test should become a standard test before any ICD is implanted is that it is completely non-invasive, inexpensive, and increases the specificity of identifying patients at risk for sudden cardiac death by almost four times (Turakhia, 2006). This would reduce the number of ICDs being implanted as prophylactics and therefore diminish the number of patients that are undergoing needless surgery, painful recovery, increased risk for depression and anger, and possibly inappropriate defibrillation therapy.

Further, off-label use of devices, such as implants for narrow QRS disorders, should be banned so that patients are not needlessly receiving a device that will not improve their condition. This will also serve to save insurers, such as Medicare, tremendous cost and ensure that those resources are available for the patients that do have a real need for an ICD. Once the patient is identified as having a condition that indicates proper use of the ICD, the complete lifestyle of the patient should be a part of the surgical considerations. As we saw with patient A.R., a physically active patient that included sports like swimming into his lifestyle, a damaged lead resulted from using a standard placement. Further lead complications have been avoided since the placement of the generator and lead set was adjusted to accommodate this activity. If physicians assess lifestyle into their procedure and technique, patients will benefit from having fewer complications when they resume their regular activities.

2. Support

We have seen from the patient interviews how crucial social support is to the heart failure patient. It becomes a requirement then that any device recipient should be enrolled in a support group to help them with their anxiety, depression, and anger as well as serve as an information source. These groups should discuss as many of the restrictions of living with an ICD as possible so that accidents like the one J.B. suffered are avoided, keep patients informed about any lead or device recalls, review new technology so that they are informed about devices before their next generator change, and provide encouragement for recovery by outlining the benefits of exercise rehabilitation. While transportation to such a group might be difficult or costly to patients, insurance companies should cover these expenses as it is an investment into the patient's health that could work to prevent their condition from worsening, requiring further costly intervention. We must keep in mind though that there are limits to the effectiveness of surrounding oneself with similar infirm patients, so a support group should meet no more than once a month.

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As above, hospital sponsored support groups are not widespread, may meet only a few times per year, and are limited in the topics of discussion. As a result, patients and their families should be advised on the availability of such groups over the Internet to connect with others to share their stories and get their questions answered. For patients like J.B., the Internet may provide the only support group available to them. The Heart Rhythm Society and American Heart Association are facilitating these connections through message boards as are private patient sites. The site users discuss their questions, perhaps because of the anonymity of the Internet, with great candor on topics some admit to not feeling comfortable discussing with their physician. The camaraderie that an ICD patient can find is quite comforting, and allows them a place to vent any anger over their situation. Some patients do not confide these feelings to close relatives or spouses since they feel it will only cause them unnecessary worry, so these online support groups in combination with the hospital sponsored ones, serve a great purpose in helping to care for the ICD patient emotionally (Tagney, James & Albarran, 2003).

Advice from an Internet support group must be treated with caution though as the advice offered is almost always that of a layperson. While the patient to patient connection is an important one, the Internet medium leaves open the possibility for someone to be pointed in the wrong direction. In these groups, patients can discuss medical issues and others might write of their own similar experience and share what worked for them. While it is comforting to the patient to hear that they are not alone, the problem lies in that there may exist other undisclosed complicating conditions, such as a background of diabetes, thyroid problems, or other heart disorders, that would make that advice invalid or possibly even harmful. Patients are advised on the home pages and legal sections of discussion groups to clear any changes through their physician; however, not all patients may heed this warning. If the patient had a direct connection to their medical staff through a regular, in-person support group as well, this would provide an opportunity to balance the advice received through the Internet.

The technologies of the newer remote monitoring systems, such as Medtronic's CareLink program that patients E.H. and A.R. are enrolled in, have to be offset with actual human contact. While being able to perform a device check from the patient's home is convenient for both the medical staff and patient, it can foster a feeling of disconnectedness from care providers. As such, it is crucial that patients be given an avenue to maintain a relationship with their providers. To accomplish this, semi-annual in-office device interrogations should become standard practice for those that are monitored remotely.

While being able to relate to other ICD patients has proven imperative, the ICD patient must also seek out ways to find support from the community they live in and think of themselves as part of that community. As Snyder writes in her 1999 poem *Dancing to the Rhythm of Life*, this will allow for bonding to others:

> What do you see when you look down from the mountaintop?
> The world sways back and forth, captured in a delicate balance.
> Daylight comes, daylight goes,
> Constant as the beating drum.
> The world invites us all to dance to the rhythm of life.
> Can you hear your children's children, as loud as I hear mine?
> Playing in a gentle world, across the gulf of time.
> Can you envision the type of world where each child has a home,
> And food to put on the plates of children of their own?
> All this beauty, all this life, and we are in command;
> Can we preserve the resources we have?
> The ball is in our hands.
> Can we hold the balance, feel the music that courses through us all?
> Will you join me; join everyone, in dancing to the rhythm of life?

The negative effects of thinking of oneself as a cardiac invalid could prove detrimental as we know from there being a mind-body connection, so by focusing attention in being part of a community that has well people, that mindset can be avoided.

Imagine again that you are the runner in the race, off course, exhausted, and still being pursued. Now imagine the friendly face of a race guide on the course that tells you how to get to the finish line quickly so you can meet up with your family. Seeing the course guide would bring immediate feelings of relief. For an ICD patient, this course guide would be in the form of a complete support program consisting of positive support groups and exercise rehabilitation to serve as the foundation of recovery Proust writes of below that will minimize both the physical and emotional the impact of the device on performing daily activities and regaining the confidence to go about life without feeling like there is someone behind you waiting to hit you with that cattle prod.

3. Exercise

> "Happily for Swann, beneath the mass of suffering which had invaded his soul like a conquering horde of barbarians, there lay a natural foundation, older, more placid, and silently laborious, like the cells of an injured organ which at once set to work to repair the damaged tissues, or muscles of a paralyzed limb which tend to recover their former movements." (Proust, p. 322).

While support plays an important part in helping patients transition, in a 2003 clinical study by Fitchet, Doherty, Bundy, Bell, Fitzpatrick and Garatt, it was concluded that a support group alone would not lead to a significant reduction in HAD scores, but that an appropriate combination of support therapy and exercise proves to be much more beneficial to patients managing their recovery, nearly cutting the average ICD patient's HAD score in half. (Fitchet, et al., 2003). Exercise plays a dual role for the ICD patient. Primarily, it will help many patients gain the strength and fitness to reduce the chances of future episodes of arrhythmias by reducing risk factors such as cholesterol, blood pressure, and fatigue. Exercise also serves a second, psychological purpose in reducing anxiety and depression because the patients feel less physically fatigued, and realize a new confidence in their bodies from being able to exercise and extend this to feeling that they are safe in engaging in normal levels of activity and recreation. Exercise is proven to help patients recover their former selves, both physically and psychologically.

As we have seen in patient A.R.'s story, insurers are willing to reimburse in some cases hundreds of thousands of dollars for patients to receive the ICD, surgery, and hospital stay. After the device is implanted though, these companies are not willing to invest in the patient's future health or quality of life medical needs, such as cardiac rehabilitation. In an interview with Carol Garber, Ph.D., FACSM, FAHA, she confirms that BlueCross BlueShield is not the only insurance company to have this policy. She told me that as little as ten to fifteen years ago, cardiac rehabilitation would have been covered for months, but as the ICD technology developed, the payment for rehabilitation dropped down to a mere ten sessions, or roughly fifteen hundred dollars per year. The reason for this is that years ago the ICD was not as developed or prevalent, so cardiac rehabilitation for heart failure patients became crucial to their survival. Now, the medical community can just insert an ICD, and survival potential is maximized, but the quality of that survival goes unaddressed. To address this problem, cardiac exercise rehabilitation programs should be covered for a minimum of one-hundred-thirty sessions. This would equate to roughly just half the cost of the ICD generator itself, and yet if the patient were to attend three times weekly, would realize a benefit of over forty-three weeks of personalized training to help them recover and learn how to gradually increase their workout intensity as their fitness levels improves.

Any rehabilitation program must obtain a baseline for each patient to assess their current fitness level. The standard for baseline fitness testing is a treadmill, stationary bicycle, or ergometer test to measure the patient's ability to reach their maximum heart rate before fatigue. The usual method of devising a patient's maximum heart rate, two hundred twenty beats per minute (BPM) less their age and then targeting exercise for eighty percent of that rate, may not be applicable for ICD patients as their device's tachy threshold rate has to be appropriately considered. For example, a fifty-year-old patient would have a maximum heart rate of one-hundred-seventy beats per minute with a target rate of one-hundred-thirty-six beats per minute. (American Heart Association, 2008). A more accurate alternative for finding a patient's target heart rate is to use the Karvonen method. To do this a patient must first obtain their resting heart rate (HR_{rest}) by taking their heart rate over three mornings before getting out of bed and averaging these numbers. They then subtract their HR_{rest} from two-hundred-twenty to obtain their maximum heart rate (HR_{max}). The HR_{rest} is subtracted from the HR_{max}, multiplied by the intensity percentage and added to the HR_{rest} (Iochelli, 2006). For example, a patient with a HR_{max} of one-hundred-seventy and a HR_{rest} of sixty striving to workout at a seventy percent intensity level would be as follows:

$$THR = ((HR_{max} - HR_{rest}) \times Intensity\%) + HR_{rest}$$

$$137 \text{ bpm} = (170\text{-}60) \text{ x } 70\%) + 60$$

The THR may also be affected by any other complicating conditions the patient may have. If their tachy threshold is programmed for one-hundred-twenty beats per minute, this does not necessarily mean the device will fire as it is also processing the morphology of the rhythm. It does however, increase the risk of an inappropriate shock if the algorithm of the device for monitoring the morphology of the electrocardiogram misinterprets while the heart rate is above threshold.

For baseline testing then, the device should be switched into a monitor only mode using the ICD manufacturer's radio frequency programming head by trained personnel. The patient should then undergo exercise testing with an AED and medical staff nearby. Once the patient completes this testing, their device should be restored, and an appropriate exercise regimen that aims to slowly increase strength and capacity should be outlined. Lampan and Knight's review of rehabilitation programs for ICD patients suggests that a three tiered approach to increase fitness levels. At the first tier, an exercise regimen that targets a heart rate of twenty BPM over the patient's resting heart rate for twenty to thirty minutes should be developed, at the second tier targeting forty to seventy percent of maximum heart rate for thirty to sixty minutes, and if the patient is interested in participating in sports, the final tier of targeting eighty to ninety percent of the maximum heart rate for thirty to sixty minutes can be outlined. We must keep in mind that from Lampman and Knight's recommendations that perhaps targeting exercise for ninety percent of the maximum heart rate would be seen as unrealistic for the overwhelming majority of cardiac rehabilitation patients. All of the exercises prescribed should keep the patient in appropriate positions so as to avoid any unnecessary pressure on the left ventricle (Lampman & Knight, 2000).

Equally important in a safe exercise program for the ICD patient is the appropriate warm-up and cool-down periods. A sudden stop to effort could result in a dangerous increase of the hormone epinephrine that might elevate the risk of a malignant arrhythmia developing (Fitchet et al., 2003). For the patient to be able to effectively follow a workout program, they will most likely require the ability to exercise independently. Many patients, especially those in suburban areas restricted from driving, would not be able to work out three to five times per week at a medical facility, so they should be equipped with an over-the-counter device, such as the Polar Heart Rate Monitor, or be taught to take their own pulse, to ensure they stay within their target heart rate ranges. Further, many ICD patients are also on antiarrhythmic drug therapy, which typically also act as diuretics, so patients should be advised to maintain optimal hydration levels. (Lampman & Knight, 2000).

We must then outline a prescription for an exercise rehabilitation routine for the ICD patient. Any ICD patient that was able to walk prior to implant should be able to and encouraged walk after. If the goal is to improve fitness beyond the basic ability to walk though, a specific program must be developed. For most patients, this will be to increase their exercise capacity gradually so that their heart rate and breathing capacity increase and they feel less fatigue overall as a result of their training. This can be done with aerobic, strength, balance, and agility training exercise. This will be beneficial to both the younger and more conditioned patients to regain their previous lifestyle, but also for older patients that may not be as fit as this can improve their balance, fatigue level, and confidence.

Under Carol Garber, Ph.D.'s advice, a fellow of both the American College of Sports Medicine and American Heart Association, the FITT (frequency, intensity, time, and type) principle should be applied when designing an exercise program to promote health in adult patients. (Garber, 2008). Garber first wants to outline that the first goal for cardiac rehabilitation patients is to regain the strength and endurance the patient previously had before their heart failure, and then move onto training for improved conditioning. Since a cardiac rehabilitation patient is usually deconditioned, she recommends starting with light exercise under careful supervision with the appropriate heart rate and blood pressure monitoring for only twenty to thirty minutes per day three to five times per week. A cardiac rehabilitation facility needs to have a cardiologist on-call in the unlikely event a patient has an arrhythmic episode during training, and an exercise physiologist and nurse on duty. In her opinion, most exercise does not need to be modified for a pacemaker or ICD patient with the exception of taking care of the device leads during the post-operative period, so patients may be limited in not performing activities that raise the arms above shoulder level. She recommends that a moderate exercise activity level that includes cardiovascular endurance training, strength improvement training, agility and flexibility exercises be performed for at least thirty minutes five times per week.

An ideal cardiac rehabilitation program would start out with twenty to thirty minutes of cardiovascular exercise three times per week with progressive increases in both time and intensity as tolerated. Cardiovascular endurance training can be done with rhythmic aerobic exercise such as walking, running or stationary bicycling, targeting maybe only fifty percent of the patient's maximum heart rate at first. As training progresses over months or perhaps even years, improved conditioning should allow the patient to target seventy to eighty percent of their max heart rate during cardiovascular workouts. Any activity that can pose a danger to the patient should an arrhythmia develop or the ICD fire should be avoided. This would mean any activity where the person could collide, fall, cause injury to others, or be moving at high speeds, just as patient J.B. should have been warned about the possibility that riding a bicycle outside could be dangerous. Along with cardiovascular exercise, strength, balance, agility, and flexibility are important training aspects that need to be included in prevention and aftercare programs.

Strength is crucial for when a person performs an anaerobic activity, such as snow shoveling, that their bodies can meet the task without causing an overexertion on the heart. Strength improvement should come from weight bearing exercise done at least twice per week, but on the opposite days of the cardio exercise. To gain strength, patients should be instructed on the proper use of a weight machine, like a Nautilus or Cybex machine, to lift an appropriate amount of weight to condition their muscles. Weights should very gradually be increased over time, and any power lifting, like a Valsalva maneuver, carefully avoided. Since the use of free weights require balance, and cardiac patients may not have yet regained this after their cardiac event, a strength improvement program that incorporates them must take this into account. At first, strength training using free weights should ensure balance by being used in a seated position. Over time as the patient improves their level of conditioning and is performing balance and agility exercises, the use of free weights can become less restrictive. Some argue that free weights are not as effective as since they allow people to use momentum to swing the weight instead of providing the control and resistance a Nautilus or Cybex type machine can and will condition the muscles better. To counter this point, patients should receive training in the proper use of any weights. This argument may also be offset by the fact that patients are more likely to be able to purchase free weights for use at home. What is really important is that patients find a way to have a strength conditioning program that they can perform properly and increase the odds that the patient will continue on with their program as a permanent part of their exercise routine. By conditioning the body, we can find that fluidity of motion, and find the improved confidence in the reliability of our bodies that will help to ward off limitations and the resulting depression. To further this confidence, we must also design in balance, agility and flexibility training at levels appropriate for each patient.

Flexibility has been added to the American College of Sports Medicine's guidelines for exercise that should be performed two or three times weekly. The reason for this is that flexibility allows us to be efficient in our movements and combat stiffness as we age. (Mullen, 2007). Efficiency in our movements will allow us to expend the least amount of energy and realize maximum result from that expenditure. This can prevent anaerobic overexertion and muscle injuries. To work on flexibility, a patient should warm up with a ten minute walk. A common misconception is that stretching is done before any exercise; however, this is false and can actually cause an injury if a muscle that has not been warmed up is stretched. After the warm up period, a patient should perform a series of training exercises that work all of the major muscle groups. It is recommended that a patient be advised by a professional, such as a physical therapist, on which exercises to perform as they will take into account the patient's activities and past injuries to come up with an appropriate regimen.

Good balance works to help all people since it is an integral part of any task to be performed. Picking up an object off the floor, ascending stairs, or even just crossing an uneven parking lot all require balance. Having it allows for the freedom to do these tasks, thus maintaining quality of life, and works to protect us from falls (Nyman, 2006). As we age, a loss of bone mass is certain and for those that lose enough mass to have osteoporosis or osteopenia, a fall from a lack of balance can lead to debilitating injury. To build balance, basic exercise like walking can help. It improves leg strength, builds overall fitness and enhances the coordination between the brain and the musculoskeletal system. For those that have built a solid foundation of being able to walk well, going up and down stairs, walking on uneven ground such as trails or hills will provide good practice. Activities such as dancing and swimming also prove to be beneficial for balance since it causes the person to move their head and limbs while maintaining their balance during movement. Should a patient be prepared physically to handle specific balance training exercises, single leg stands, trunk turns, single leg squats, and marching in place with eyes closed are all options for training at home. (Weight Master, 2007). Ideally, a patient can perform balance exercises at any time without regard for it being a cardiovascular training day or strength training day. If they are capable, walking outside can serve to be their cardiovascular and balance training at the same time. As walking, dancing or swimming can serve multiple training purposes at once, so can Tai Chi.

Movement exercise like Tai Chi training can assist with strength, balance and agility training as it is a series of fluid, slow motion exercises. The Mayo Clinic's (2007c) website describes is as "meditation in motion" as it focuses on "rhythmic patterns of movement that are coordinated with breathing." Tai Chi has been proven to help patients to improve in these areas after illness. Agility is the ability to stop and turn quickly, and the more agile the patient, the safer and more efficient they will be as they perform daily activities, and again, minimize the risk of a cardiac event or injury. In addition to Tai Chi, patients can also work on agility with simple exercises like walking in circles, walking backwards and sideways, or even setting up a series of cones, or paper cups, and weaving around them. The pace is not important so even the most deconditioned persons can start slowly and build up their pace and challenge over time. Agility exercise though should be performed only after a warm up, so walking for ten minutes prior is important, or agility training could follow a cardiovascular exercise training session. Going back to Tai Chi, we see multiple facets of physical health being improved with one enjoyable activity. By finding activities that serve multiple functions, patients are more likely to approach their rehabilitation or exercise program positively and not view it as such a time consuming chore. Further, Tai Chi's meditative aspect helps patients to start making the mind-body connection.

Tai Chi

4. Mind-Body Connection


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According to Mala Cunningham, Ph.D., the mind-body connection is an important one. Emotions can affect our physical health and healing process. People that experience bouts of depression typically complain to health care providers about more physical aches and pains than non-depressed patients. Illustrating this concept is the decreased the HAD scores of post-operative ICD patients that came from being part of an exercise program. There is a reciprocal effect from this connection—when we work to control our minds, our bodies follow suit and when we are more confident in the ability of our body, our emotions are elevated. When our emotions are elevated, we feel less stress and anxiety. Managing stress is an important goal for everyone and especially cardiac patients since the stress responses can trigger arrhythmias. To accomplish this connection, patients are not limited to just Tai Chi, but have a wide variety of training options.

Americans have imported many types of yoga over the years. Hatha and Iyengar are some of the most commonly taught traditions. Hatha yoga teaches the poses (asanas) that are easy for patients to learn and combines it with regular breathing (Pranayama). This could be especially useful right after an appropriate cardiovascular workout after the cool down period. Cardiovascular exercise will elevate the patient's heart rate. While the proper cool down after the workout will protect against an inappropriate release of epinephrine, by performing a yoga training session after the workout, the patient will learn to bring their heart rate down to a rate well below the tachycardia threshold while improving their posture and balance. Iyengar yoga can be used in a similar fashion, but carries with it an added benefit of incorporating strength and balance training while being adapted for more deconditioned persons by utilizing equipment like blocks, straps and cushions. Similar to Tai Chi, Iyengar also moves at a slower pace than Hatha, so some patients may find it easier at the start of their rehabilitation program to follow this tradition. (The Different Types of Yoga Explained, 2008). In either tradition, poses must be modified so that patients are not increasing left ventricle pressure, like the plow position would,


Left: Yoga Plow Position as Inappropriate Pose for ICD Patients
Right: Yoga Lotus Pose as Example of Appropriate Pose for ICD Patients
© Lev Dolgachov, 2008

and remain in upright or mostly upright positions. In addition, yoga traditions that utilize methods that could prove to be too stressful or unsafe for cardiac patients, such as the extreme heat of Bikram or Ashtanga yoga, should be avoided.

Another option to yoga or Tai Chi is Qigong training. According to Lee, Kim, Huh, Ryu, Lee and Chung (1999), Qi-training is shown to be effective to reduce blood pressure and heart rate in a study done on healthy individuals. In their study, subjects trained for, "one hour per day, six times a week, and was directed by a mater. In this experiment, 1 h of Qi-training consisted of three stages: sound exercise (reciting Chunmoon-eight lines of fifty one meaningless words) for ten minutes, motion for ten minutes and meditation for forty minutes." (p. 174). The motion exercises of Qi-training focus on moving the Yin and Yang energies through the body, and when combined with the meaning less word chant prior and meditation period after, have a positive effect in controlling the heart. The choice of yoga, Qigong or Tai Chi is not nearly as important as the patient finding an enjoyable training method that helps them to make the mind-body connection so that they can learn to control their energy to focus on health and healing. Finding the right activity is important so that the patient is more likely to perform the exercise for the long term. If cardiac rehabilitation centers offered trial courses on each discipline, patients could test the waters to help them find the right activity for themselves. Further, in addition to training on these disciplines, patients should also receive training to learn to control their stress and heart rate in daily life situations.

5. Stress Reduction

> "Here it is enough to mention that Merleau-Ponty's view of language as a thoroughly incarnate medium, of speech as rhythm and expressive gesture, and hence of spoken words and phrases as active sensuous presences afoot in the material landscape (rather than as ideal forms that represent, but are not a part of, the sensuous world)—goes a long way toward helping us understand the primacy of language and word magic in native rituals of transformation, metamorphosis, and healing. *Only if words are felt, bodily presences, like echoes or waterfalls, can we understand the power of spoken language to influence, alter, and transform the perceptual world….*
>
> To neglect this dimension—to overlook the power that words or spoken phrases have to influence the body, and hence to modulate our sensory experience of the world around us—is to render even the most mundane, communicative capacity of language incomprehensible." (Abram, p. 89).

In mimicking the runner ahead of you—the timing of their footfalls, the cadenced breathing, their stride—you have found yourself a pace runner. You will follow them because you think they know how to push through all the mental blocks of a marathon distance to finish this race, and by simply embracing their rhythm perhaps you can finish as well. Rhythm, so greatly underestimated, finds an important role in many of the things we do. It is defined in the physiological context as "the regular recurrence of an action or function", but in speech it becomes "an ordered recurrent alternation of strong and weak elements in the flow of sound and silence". (Merriam-webster.com). Just as an orchestra follows its conductor moving his arms to lead each section and provide the visual metronome, rhythm leads many of the everyday things in life. We read aloud to babies, not because they understand the story or even the words, but because the rhythm of our language provides comfort. We lay a baby's head on our chest so that they hear our slower heart and it influences theirs to slow down and fall asleep. We run or exercise to a favorite song because the beat inspires us to synchronize ourselves to it and keep going. Our senses allow us to absorb rhythm from the world around us and our minds allow us to use it to our benefit.

These tools of rhythm exist in the world around us, but can we use it for cardiac arrhythmias? The learned process of biofeedback, as defined by the Association of Applied Psychophysiology and Biofeedback (AAPB), is described as a process of being able to:

> "alter brain activity, blood pressure, muscle tension, heart rate and other bodily functions that are not normally controlled voluntarily. Biofeedback is a training technique in which people are taught to improve their health and performance by using signals from their own bodies." (AAPB website, 2008).

Essentially, a patient can undergo a series of training exercises to control their body, including their heart rate. A patient is typically connected to a device through skin electrodes that will measure the above listed stress responses, and display this information to the patient with a signal, like flashing a light. The patient watches the device, and then learns to control these stress responses through meditation and visualization to make the light flash slower and slower until an optimal level is reached. Here is where the importance of language comes in. As Abrams describes, language carries an intrinsic rhythm, and biofeedback patients are typically trained to repeat a word or phrase in their mind to which they slow and synchronize their stress responses. With these tools, patients are changing their bodies and healing themselves. By controlling their heart rate, the patient can potentially stop an arrhythmia before it even starts.

The National Institutes of Health (NIH) sees biofeedback as a viable tool in the fight against heart disease, and for some patients, an alternative to pharmacological intervention and is currently conducting studies to provide evidence of its effectiveness, with expected completion of these studies in 2009. The NIH's position is that while drugs may be effective at controlling the patient's heart rate, the quality of life may be reduced with these antiarrhythmics. Commonly prescribed drugs, such as Amiodarone, come with side effects warned by the United States Food and Drug Administration (FDA) such as tremors, palpitations, nausea or vomiting, vision problems, and possibly worsening an arrhythmia or causing pulmonary toxicity. (United States FDA, 2006). By contrast, biofeedback carries no negative side effects with respect to cardiac arrhythmias. The Mayo Clinic even endorses biofeedback training as having the ability to reduce a patient's dependence on medications, or do away with their need all together. (Mayo Clinic, 2008). With the ability control heart rate and rhythm to reduce a dependence on pharmacology, the ability to reduce the need for surgical intervention, the implantation of either a pacemaker or ICD, also emerges.

There are limitations on the effectiveness of biofeedback. Many patients will enter into an arrhythmia during sleep and if they are asymptomatic, will not wake to be able to utilize their biofeedback training to control their heart rate. Biofeedback still proves somewhat useful in this scenario as a patient that has completed biofeedback training experiences reduced stress levels overall, thus it lowers their risk of heart disease or a worsening of heart disease, and the patient entering into a life threatening arrhythmia in the first place as stress can be a trigger for these events. In addition, organic conduction disorders, such as long QT syndrome, will not benefit from biofeedback as the problem does not originate in the heart's ability to vary or control the heart rate, but rather comes from the heart's inability to pass the electrical signal to contract from the atria to the ventricles properly.

We know there is rhythm in language, song and almost every part of our environment, and using the power that exists within them, as Abram suggests, can provide patients with an internal pace runner; a biofeedback tool they can call on to help transform themselves into a well person. Combining this rhythm into a life that includes a healthy diet and exercise would go a long way to prevent acquired heart disease, like coronary heart disease, and minimize the risk factors that can worsen an organic conduction disorder.

Biofeedback training methods discussed would serve useful to assist a patient to control their heart rate in stressful situations. By controlling their stress reactions, patients are minimizing their cortisol levels elevating. Elevated cortisol levels increase blood pressure, and if a patient's blood pressure goes too high, a cardiac event is more likely to occur. Another tool patients can call on to help them calm down is to perform the breathing exercise outlined by Dr. Andrew Weil to avoid an arrhythmia as patient J.B. does. This exercise is simple, and can be performed anywhere. The patient is instructed to sit up straight, place their tongue against the roof of their mouth behind their front teeth, and exhale completely. Then they close their mouth and inhale through the nose for a count of four, hold that breath for a count of seven, and exhale through the mouth again for a count of eight. They only need to breathe like this four times to experience the reduced, controlled heart rate. (Weil, 2008). While improving conditioning and controlling stress levels will greatly assist patients in both a preventative and recovery aspect to heart disease, patients should also work to find activities that merge these aspects, such as dance.

6. Dance

To compliment the psychosocial support of support groups, and further both emotional and physical health, patients should try dancing. When we think of dancing, we usually think of times of joy. We dance with others at happy events like weddings and parties. Since a cardiac patient can utilize that joy for healing purposes, they need opportunities to dance at regular intervals since weddings and parties are infrequent. Dancing with family is enjoyable as grandchildren are usually interested in activity, local dance schools that offer classes are a possibility as are community performance groups such as square dancers. Similar to the choice between yoga, Tai Chi or Qigong training, each patient has to find the courage and self-discipline to try out various kinds of dance and find the group that is right for them. Finding the right group can be so important in building support as becoming involved in a group that has a clique mentality that shuns new members, or becomes so overwhelming that it preoccupies the patient can actually serve to be detrimental. Patients should be involved with a variety of groups, both ones where they are interacting with cardiac failure peers to gain support in that context, as well as groups of well people so that their condition does not take over their life. The goal is to find a positive balance, and have support coming from many directions.

7. Nutrition

Dietary changes and guidelines can vary from source to source, but proper nutrition will aid in the prevention of heart disease and work to reverse heart disease in acquired cases. What patients need for the immediate post-operative recovery period is a general guideline to work with until an individualized plan can be provided. Two sources offer plans that most patients can use. The American Heart Association recommends a low-fat but balanced diet that includes food sources from each food group. Another approach that is proven to work is the low-fat vegetarian diet Dr. Dean Ornish recommends. Under the Ornish plan, the reversal of heart disease requires a patient to follow a vegetarian diet that eliminates simple carbohydrates and focuses on complex carbohydrates. (Pearce, 2003). An example of this would be to choose a whole grain bread over a white bread. Fat must be limited to only ten percent of the diet, and fruits, vegetables, and beans or other soy based proteins will work not only to achieve weight loss, but lower cholesterol levels, a risk factor for heart disease. (Pearce, 2003).

Omega-3 Rich Grilled Salmon
© Nikos Vlasiadis, 2008

From researching the various plans, it seems the Ornish plan has the clinical evidence to produce the greatest reduction in weight, cholesterol levels, and atherosclerosis. Due to the extremely low fat levels though, this plan should not be followed for the long term. It should be an introduction to the dietary overhaul patients need to make to get a quick result in reducing risk factors, and once the patient is within safe levels, more fat levels, especially sources of Omega-3 fatty acids that come from fish and nuts should be reintroduced, possibly targeting a fat level of thirty percent. Portion control should also be understood so that patients understand to control their diet through both what they are eating, and how much. There are so many published diets geared towards reducing risk factors for heart disease that the problem arises to provide a plan that is right for all cardiac patients permanently.

There is no way to make a blanket policy in this area, despite some medical professionals' attempt to do so, as in the case of a local chiropractor and licensed clinical nutritionist I interviewed that made recommendations based on blood type. This approach is widely panned, and the need for individual assessment becomes a more logical way to work with patients. The solution then becomes for cardiac patients to be able to see a nutritionist or dietician. In a consultation with a professional, the patient's medical history and any complicating conditions, such as diabetes or anorexia, will be figured into the equation, along with a review of the patient's body composition, current weight and body mass index. A diet plan will then be outlined, with the good sense general dietary guidelines, such as the lowering of cholesterol levels, incorporated.

In my interview with Jason Sholder, Ph.D., he acknowledges the importance of a proper diet in preventing and reversing heart disease in acquired cases, however, stipulates that organic conduction disorders are not affected by diet so that a patient with a bundle branch block can not expect to reverse their condition through diet or exercise. What he does say though is that a proper diet and exercise program for these patients will work to minimize any damage to the heart as an organ, so organ failure risk is minimized and any disease, such as coronary artery disease (CAD) that would work to complicate the conduction disorder is avoided. By understanding proper nutrition for their bodies and incorporating the self-discipline to make the necessary changes, the patient will be equipped with the physical tools to improve their condition.

8. Patient Responsibility

At this point, we must step back before looking at industry and revisit the role of the patient in their own care. If we can create the environment for patients to have access to proper assessment, exercise training that includes cardiovascular, strength, flexibility, balance and agility fitness and couple that with dietary and psychological counseling, what can a patient such as J.B., A.R. or E.H. do to maximize their quality of life? On an individual basis, there are recommendations for even the most motivated of patients.

J.B. is left after his implant with anger and depression issues resulting from a serious, life-altering brain injury from his arrhythmia and ICD. He takes prescription medications for these issues, but more can be done. While J.B. remains physically active and performs breathing exercise to try to control his stress, he must further the mind-body connection. In my interview with J.B., I could discern that his emotions are down. He does not have a family but for two siblings that live far away. It is recommended that he find an in-person support group so that he can vent his anger over his situation, and benefit from the guidance of living with his device from other members. If an in-person support group is still unavailable in his area, then he should participate in an Internet based group on a limited basis, for only a few hours per week. Another issue that would help him is to further his stress management and improve the balance issues he has from his injury with Tai Chi. Tai Chi is recommended over Qi-training for J.B. because he suffers from memory issues to this day, and the complex Chunmoon chant would probably not be something he is able to remember. Biofeedback training would also be useful for this patient as another stress management tool. Another avenue of change for J.B. would to consider switching to a Medtronic ICD after his St. Jude unit's battery depletes. Patients A.R. and E.H. have either improved or not had negative complications with their Medtronic ICDs. With the stress and anxiety issues addressed, also recommended for J.B. would be meeting with a nutritionist. J.B. still suffers physical effects, like a recurrent infection in his heel, from his stay at the nursing home. If his nutrition improved, then perhaps his body could better fight off the infections and allow this problem to heal. Nutrition is an important aspect of recovery that patient E.H. needs to examine in her recovery plan as well.

After her ICD, E.H. knows that her lifestyle needs changes, but she lacks the motivation to make them. When I asked her why, she said she did not really know why she does not make them and attributed it to old habits dying hard. The proper education as to the benefits of incorporating an exercise, diet and stress management program would provide this motivation. It would be recommended that E.H. begin to improve her cardiovascular, balance, and agility with walking at a brisk pace for thirty minutes three times per week. She then needs to incorporate strength training exercises as advised by a physical therapist using ten pound dumbbells three times per week on the opposite days, and gradually increase the weight over time. This will help E.H. meet the demands of her exhausting work schedule, and being female, help her to avoid osteoporosis. A meeting with a nutritionist is definitely in order for E.H. as her ejection fraction is very low, and all of the exercise training she will do will not be as effective if her diet does not help her to clear her arteries and allow the heart to improve its output.

E.H. seems to have transitioned well psychologically to having an ICD, but an attending in-person support group would still be beneficial to her since she does communicate that her enrollment into CareLink has her feeling distanced from her medical providers. She should also be sent into the office for interrogation on a semi-annual basis to address this issue. Finally, yoga would be recommended for E.H. for the purpose of stress management and maintaining flexibility. With a physically demanding job that demands a high number of hours, E.H. could find relaxation with yoga training after her cardiovascular workouts, and improve her flexibility to meet the physical needs of her job.

Patient A.R. is a challenge to examine for areas of improvement due to his being so proactive and involved in his rehabilitation. One potential problem I can see is the emotional dependency on his dog, Buddy. While the wonderful relationship between the two is truly a special gift in each others lives, I worry about A.R. if Buddy should for some reason fall ill or pass away. If that were to happen, I would worry that A.R. would lose his motivation to continue on with his perfect cardiac rehabilitation efforts. To counter this possibility, I do think that A.R. should involve himself in another activity or two that does not include his dog, and establish more social connections should he need to call on them for support as he did in his previous depressed period. Finding a fun activity like dancing might help him to create more social connections to well people. I do also encourage A.R. to start the ICD support group in his area as not only will he help others, but himself as well.

9. Industry Changes

Now that we have proposed solutions for patients and created the environment for them to take advantage of the tools to improve quality of life, another important direction that support should be coming from is the device industry. We must correct an industry failure to properly warn patients about the reality of an ICD shock as not being just a small thump in the chest, but to explain that a defibrillation shock has a wide range of power. By not warning patients, when they do experience an actual shock, they are left feeling betrayed and angry at their care providers and device manufacturers. An ICD can administer various levels of therapy based on the rhythm pattern it detects such that a small cardioversion shock may be appropriate or a true defibrillation shock of over seven hundred volts might be required. A patient must be prepared for this so that accidents like the one J.B. endured are avoided. The industry must also work to correct the percentage of inappropriate shocks, over thirty percent, a figure that stunned Jason Sholder in our interview, being administered. Technology must be developed and the algorithms in ICDs continuously refined so that better detection of true instances ventricular fibrillation and tachycardia are sensed. As the patient will be fully conscious when an inappropriate shock is delivered versus the strong possibility that they would be unconscious if in a true ventricular tachycardia or fibrillation, the patient will certainly experience the pain of the shock, and their anxiety and depression will worsen.

The industry must also find a way to regulate the marketing pressure it puts on physicians that can create ethical dilemmas. Sponsoring research to create partnerships with medical students or even large cardiology practices, sweetheart consulting arrangements, and direct patient marketing campaigns create a demand on the physician to select devices from the sponsor company. While there is no doubt that the industry realizes its technological advances from the research and clinical trial data gathered by its consultants, the payment for these services should be in line with the work performed to avoid the appearance of any impropriety. There must be a system in place that ensures that the device selected for a patient is the best possible choice based on feature set, regardless of the manufacturer. A review panel should be established in each state that will randomly review implant choice by the physician in an effort to hold the doctor accountable for their device selections. If physicians had to answer to an independent authority, it would work to avoid patients receiving a device that may not be the best option for their condition. Direct to patient advertising campaigns should also be suspended as the complex decision to implant something into the body should not be driven by emotional television ads promising peace of mind to those with heart failure.

10. Reimbursement Reform

Many of the problems that we are seeing in the aftercare issue results from the ongoing problem that doctors are being forced by reduced Medicare and insurance reimbursements to try to see as many patients as possible in a day to maximize profitability. In Jason Sholder’s opinion, cardiology reimbursements have taken some of the worst hits but yet heart disease is the number one cause of death in patients. This must be resolved to allow for a fair payment to physicians for visits and procedures. If a physician is not under pressure to move through a tightly packed schedule and treat their patients as something of a production line, patients will be best served in understanding their risk factors for heart disease in the prevention phase, or possibly have all of the appropriate guidelines for improved health and warnings explained to them after receiving their device.

Further, Medicare and insurance companies need to invest as much into prevention and aftercare as they do into procedures. Simple and relatively low cost diagnostics like stress tests and CT angiograms, are not covered as a part of routine physicals when doing so may save patients, like A.R. from disastrous cardiac events that then require a series of high-cost interventions. Since cardiac death is the leading cause of death in Americans, insurance companies need to pay for testing that can monitor if and when patients are heading into dangerous conditions. Most patients have estimated the cost of receiving an ICD upwards of ninety thousand dollars, and yet, cardiac rehabilitation, if they are lucky enough to receive a prescription for, only is covered for a handful of sessions. Cardiac rehab not only performs a physical purpose, but as Carol Garber, Ph.D. describes, can work as a social support as well since the patients are able to connect and exercise with other heart failure patients. The question arises though that if we provide for a higher reimbursement to physicians and force insurance companies to invest in prevention and aftercare, as to who will pay for this increased cost.

11. Taxation Overhaul

The answer to the payment question requires an overhaul of our current taxation system. Jason Sholder proposes a flat tax system that eliminates the loopholes for the wealthy and is more equitable across all income levels. For example, a ten percent flat tax would have a person earning twenty thousand dollars annually paying two thousand dollars in taxes, and one earning two hundred thousand dollars paying twenty thousand in taxes. In the United States taxation is relatively low as compared to our European counterparts that are subject to higher taxation levels. The price for this lower taxation though is lower services. We have to decide that health care is a worthy investment, and move to increase the funding in an equitable manner.

12. Purchasing Controls

Finally, we must trim the unnecessary costs out of procedures and devices like ICDs. According to our interview, Jason estimates the cost to manufacture a pacemaker at five hundred to one thousand dollars, and an ICD for under two thousand. Given this, why does a pacemaker cost about eight thousand and an ICD over forty thousand? His answer is simple, supply and demand. ICD use is soaring so the demand is there, and ICD manufacturers are commanding a high price for their supply. Adding into this mix are the unethical purchasing procedures of hospital purchasing groups that negotiate volume discounts on the devices, sometimes even purchasing them at half the list price, but yet still billing Medicare and insurance companies the full list price thereby realizing a profit upwards of twenty thousand dollars in some cases. Since these are prescribed devices that are for sale only to or on the order of a physician, the insurance companies can not purchase the devices from the manufacturer or require a copy of the device invoice to perform a true reimbursement analysis. We must reform the system to allow for some kind of cross check to ensure truth in billing. Insurance companies should be allowed to require a copy of the device invoice from the hospital or purchasing group so that they can reimburse the appropriate amount instead of a falsely inflated price. This will make the tax reforms outlined above work to serve more patients since the collected tax dollars will be more wisely spent and provide devices to more patients.

13. Future of the Technology

Given these changes to both the prevention and aftercare, industry changes to warn patients and reforms to the medical reimbursement system, we must look to how the future can help heart failure patients. Devices like pacemakers and ICDs have come a long way to being small, effective, and greatly improve quality of life. The question then becomes of how in the years beyond two-thousand-eight will these devices change to work even better? The expert I know in this field, Jason Sholder, Ph.D., was able to shed a great deal of light on the issue. I asked Jason about the future of pacemakers and ICDs. With pacemakers being capable of delivering tachycardia pacing, and ICDs delivering bradycardia pacing, would we see an eventual melding of an all-purpose device? Jason says no, that it wouldn't make sense to put technology into a patient at a higher cost than necessary. What Jason did share though is that pacemakers and ICDs just control the rhythm of a person's heart and that this is just one side of the equation. When he was COO at Impulse Dynamics, they developed a device, call the Optimizer which is currently in clinical study that improves the stroke volume of the heart. Increasing the stroke volume of the heart is really the goal of exercise training, so the fact that a device has been developed to assist with this function is important. This is crucial because the heart's output, or ejection fraction, is a clear predictor of sudden cardiac death (SCD). The higher the output, the less likely a patient is to experience SCD. Jason believes this device will prove to be a great tool in the fight against heart disease as it helps all types of heart failure, even narrow QRS disorders. We may see that technology someday integrated into a pacemaker or an ICD so a device is controlling both rhythm and output, but again, we will probably not see one all-purpose device.


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> "No, for new lands, created by the collision between technology and life, loom on the horizon, unknown lands peopled by strange and confusing lifeforms, undoubtedly intelligent but strangely unconscious, neither completely alive nor dead, never completely human, lifeforms rising from the burning ashes of our binary world. The world around us is rich with strange new realms born from the coupling of living tissue to metal." (Dyens, p. 1).

Dynes' description of the merging of the human body with electronics may strike us on the superficial level as something out of a Star Trek movie, evoking images of androids or other foreign lifeforms. What this view is though is one that extrapolates an already present situation. We are merging technology into the body, like pacemakers and ICDs, to keep people alive. With this partnership we do see complications arise from the fact that we are able to fix a medical problem, a rhythm disorder, but that solution creates a variety of other problems for the patient in stress, anxiety and depression. The current situation treats the patients as some sort of production line in that they are lined up for surgery, the mechanical process performed, and the patients are sent home. There is no point in keeping people in the technical definition of alive if we can't allow them to live. To live the patient has to have a quality of life that is perceivably similar or better than the one they had before implant. Pacemakers and ICDs continue to work after a patient's body dies. This does not keep the patient alive. It is the sum total of all of the tissue, organs, soul, mind, *and* the electronics working together peacefully to fit this definition. The goal of ICD and pacing therapy should be one that makes the dance of life a harmonious one between the human body and this technology. Using the solutions provided herein, the medical community can have a coordinated paradigm that addresses every physical and psychological aspect of the patient's care.

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Appendix A

ICD Implantation

HOME CARE INSTRUCTIONS

Your ICD is a: ____

Your ICD doctor is: ____

The following discharge instructions are intended to guide you through your recovery and follow-up of your ICD implantation. The goal is for you to resume your normal activities of daily living while living with your ICD. Please call the Arrhythmia Service at **615-322-2318** if you have any questions.

Incision Care

- Keep your incision dry for 7 days. **Do not get the incision or bandage wet.** You may sponge bathe but may not shower for 7 days.
- After the pressure dressing is removed, you will have steri-strips over the incision. Do not remove them. Allow them to fall off on their own.
- Do not apply lotions, powder or ointments to the incision.
- A bruise or mild swelling is expected and may take several weeks to heal.
- **Notify your physician if you observe an increase in swelling, drainage, bleeding or if you develop a fever of 101°F or greater.**

Activity

- Avoid stretching the arm on the side of your ICD above shoulder height or behind your back for 2 weeks.
- No sudden, vigorous, pulling or chopping movement with your affected arm for 4 weeks.
- Wear a sling only if you need a reminder to limit activity. It is important to use the arm for limited activity and not keep it still.
- **Walk!** Walking is encouraged. Start gradually and increase daily.
- Do not lift more than 10 lbs. with affected arm for 2 weeks. Do not lift more than 20 lbs. for the first month.
- You cannot drive until you have your doctor’s approval.
- Swim using precautions for safety.

Safety Precautions

- You may use common household appliances if they are in good repair. **This includes using a microwave oven**.
- When using cellular phones and cordless phones:
  - –Keep at least 6 inches from the ICD and use on opposite ear from the ICD.
  - –Store the phone in a location opposite the side of the ICD even if not in use. Do not keep it in your shirt pocket.

(continued)

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- Keep power tools properly grounded. Chain saw use is not recommended.
- Do not hold or carry magnets near your ICD.
- Avoid electrical arc welding.
- Airport screening devices and theft detectors may alarm but normal movement through and away from the detectors should not harm the ICD. You will need to show your ID card and ask for a hand search. The hand held metal detector (wand) contains a magnet and may not be placed near the ICD.
- Medical Procedures — always tell any health professional that you have an ICD and show your ID card. If you are going to have surgery or cautery, your ICD may need to be turned off or reprogrammed.
- **Do not have a MRI (Magnetic Resonance Imaging Study) or Therapeutic Diathermy. If you are having radiation or lithotripsy, certain precautions need to be taken before the procedure.**
- Exposure to normal diagnostic x-ray, cat scan, and fluroscopy radiation will not affect your ICD.
- Sexual activity may be resumed when you feel ready. Your partner should not worry about electrical shock.

Follow-up Care

- You will be given an appointment for a wound check in 5-7 days: ______________________
- You will need to follow-up with your ICD physician in 4-6 weeks and will need continued follow-up for the rest of your life. Your 4-6 week appointment is: ______________________
- If you receive one shock and feel okay, notify us of what you were doing and how you felt afterwards. Please call during office hours at 615-322-2318. We will set an appointment for you to come in and have your ICD checked.
- If you receive more than one shock and do not feel well, **call 911** and go to the ER. The physician at the ER will notify us. Be sure to have your ID card.
- If you receive a shock and become unconscious, bystanders should call **911 immediately** and start CPR.
- Notify us if you change your address, telephone number or doctor, and also if you plan to take an extended vacation.

ICD ID Card and Patient Booklet

- You will be provided with a temporary ID card at time of discharge from hospital. The manufacturer will mail a permanent, plastic card in approximately 8 weeks. **It is extremely important that you carry your ID card with you at all times!** It is not possible to check the ICD without knowing the manufacturer and model number.
- Please refer to the ICD booklet for further information on the ICD.
- We request that you obtain a Medic Alert necklace or bracelet. You can pick up an application at most drug stores.

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