

Author: Helen McFarland, 2014

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INTRODUCTION

The inspiration for the book, *ICD Connection: A Collection of Patient and Family Stories*, stemmed from our annual University of Michigan Young ICD patient and family support conference. This conference, “The Young ICD Connection Conference,” is a multidisciplinary collaboration and is coordinated and hosted by the University of Michigan Cardiovascular Center and Congenital Heart Center cardiology staff. This conference was established in 1995 when we identified that young ICD recipients (children, teens, and young adults) have physical and psychosocial issues unique to their developmental age and differ significantly from our older adult patients. The indications for ICDs were expanding at this time and many young individuals felt isolated and alone. Survey results from our support conference reflect overwhelmingly positive feedback for the morning general session where a panel of patients and family members individually share their personal ICD stories. Patient and family stories highlight how the ICD implant affected their life, their challenges and struggles along the way, and share what was and wasn’t helpful to their moving forward and adjusting to life with an ICD. The opportunity for these patients to share their experiences and interact with peers who have had similar experiences can facilitate personal growth and wellness on their life journey with an ICD.

Theresa Davidson, RN

Laura Horwood, NP

(founding members of the Young ICD Connection Conference)



Frequently Asked Questions about Implantable Cardioverter Defibrillators (ICDs)

*Laura Horwood, NP
University of Michigan Hospital*

Q. What is an implantable cardioverter defibrillator?

An implantable cardioverter defibrillator (ICD) is an implantable electronic device that provides immediate therapy to a life-threatening arrhythmia (heart beating too quickly) via a painless pacing sequence or a jolt of electricity. It can also act as a pacemaker if the heart is beating too slowly.

Q. Why might a person need one?

Numerous underlying heart conditions can cause a weakening of the heart muscle and can predispose an individual to develop or be at risk to develop life threatening ventricular arrhythmias. For adults, the most common condition is coronary artery disease leading to ischemic cardiomyopathy (where the heart can't pump enough blood to the rest of the body). There are also a number of inherited conditions that can cause a person to have sudden life threatening ventricular arrhythmias. Examples include hypertrophic cardiomyopathy, long QT syndrome, Brugada syndrome, CPVT, LV noncompaction and arrhythmogenic right ventricular cardiomyopathy.

Q. How does it work?

The implantable device continuously monitors the heart's rhythm and is programmed to deliver "pacing impulses" to restore its natural rhythm, which would avoid the need for a shock. If pacing is unsuccessful, it will deliver a shock to the heart.

Q. Where does it get implanted?

The device is implanted under the superficial skin tissues in a preformed pocket in the left or right pectoral area. The leads are

inserted into the large subclavian vein and threaded into the heart and then secured within the right heart chambers.

Q. How does my doctor determine if I need an ICD?

Through a comprehensive evaluation that includes history and physical exam, echocardiography (using sound waves to see the heart), and electrocardiography (measures heart's electrical impulses). Sometimes the individual may require further tests such as a nuclear stress test, cardiac catheterization and cardiac MRI.

Q. How big is it?

It's slightly smaller and thinner than a stop watch.

Q. How much is the ICD going to protrude from my chest?

It depends on the person. It also depends on the type of implant that you receive. Some of the implants are very small, and some are a little bigger. If you're thin, it generally will protrude. If you have a little more bulk it won't be so obvious. The device can be implanted under the chest muscle, which would prevent it from being as noticeable. Speak to your physician about options for your implant location.

Q. What does a shock feel like?

Some people say they felt like they were kicked in the chest by a horse. Others describe the shock as like being hit in the back. In general, patients will agree that the shock is uncomfortable; however, it is quick and there is no lingering discomfort.

Q. What should I do after a shock?

First thing, you should sit down. It's possible that you could pass out prior to a shock or should a second shock be required. You want to make sure you don't fall and/or hit your head. Call your doctor's office and let them know you received a shock. When patients receive a shock, it is important to have the device evaluated to make sure the device is working properly and to document your arrhythmia

episode. Your device may be evaluated remotely by a home monitor. However, if you have received multiple shocks or you are having symptoms, you will be directed to your doctor's office or the emergency room to be evaluated depending on your individual situation.

Q. Can I still work with an ICD?

That depends on what you do for a living. Most people with an ICD are able to continue working. Speak with your doctor about your occupation.

Q. Will people be afraid to touch me?

No. Even if someone does touch you when you are shocked, it won't hurt the other person. They may feel a tingle, like getting a static shock from the rug.

Q. I feel scared and depressed. Is this normal?

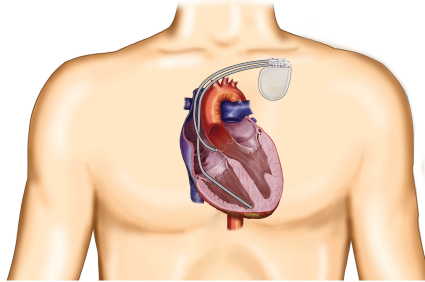
This is absolutely normal. In the beginning, many people worry about the shock and if and when it will happen. Some people don't even know they're in a ventricular arrhythmia when the device fires. However, other people have had an ICD for years and have never experienced a shock. Joining a support group and meeting others who share your fears can address feelings of being alone. If you're having anxiety or panic, you can speak to your doctor about anti-anxiety medication in addition to counseling with a social worker or psychologist.

Q. Are there different kinds of ICD's?

Yes.

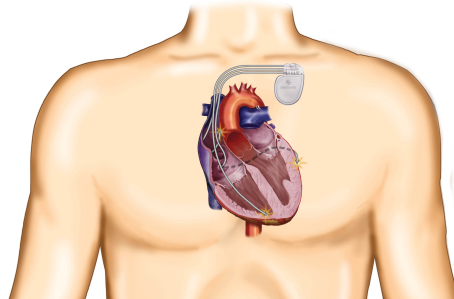
- a. There are ICDs that have leads in just the bottom chamber (ventricle) or in both the top and bottom chamber (atrium and ventricle). Generally speaking, those individuals who do not require heart rate support (pacing) and don't have other rhythm issues

(atrial fibrillation, atrial flutter, atrial tachycardia) will only need a single chamber ICD. With these devices, leads are placed within the heart and can terminate ventricular arrhythmias with pacing therapy (painless) or shock therapy.



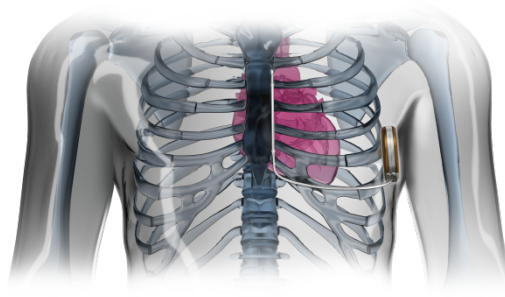
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- b. There are ICDs with three leads located in the atrium, right ventricle and a lead that is tunneled through a vessel to the left side of the heart. The two bottom chamber leads serve to provide simultaneous pacing of the ventricles and over time can help to make the heart muscle stronger with fewer symptoms of fatigue and shortness of breath. With these devices, leads are placed within the heart and can terminate ventricular arrhythmias with pacing therapy (painless) or shock therapy.



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- c. There is new device technology where the ICD and lead is placed subcutaneously (under the skin and fat tissue). These devices can only provide shock therapy to terminate life threatening arrhythmias. At this time they will not provide long-term heart rate supportive pacing and are unable to provide pacing to painlessly terminate your arrhythmia. Currently, only a subset of patients are considered for this type of device therapy.



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