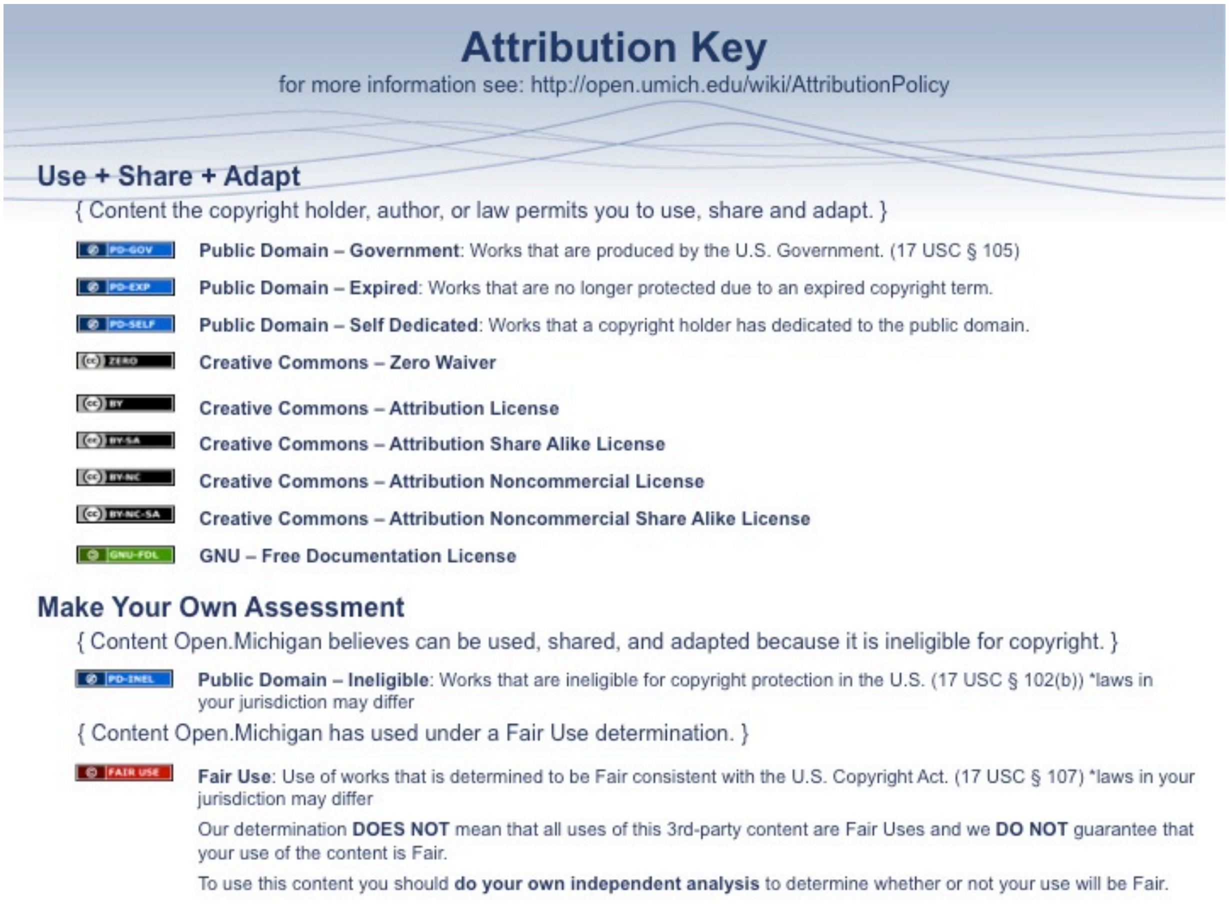
Author(s): Helen McFarland



Attribution Key

for more information see: http://open.umich.edu/wiki/AttributionPolicy

Use + Share + Adapt

{ Content the copyright holder, author, or law permits you to use, share and adapt. }

PD-GOV **Public Domain – Government**: Works that are produced by the U.S. Government. (17 USC § 105)

PD-EXP **Public Domain – Expired**: Works that are no longer protected due to an expired copyright term.

PD-SELF **Public Domain – Self Dedicated**: Works that a copyright holder has dedicated to the public domain.

ZERO **Creative Commons – Zero Waiver**

BY **Creative Commons – Attribution License**

BY-SA **Creative Commons – Attribution Share Alike License**

BY-NC **Creative Commons – Attribution Noncommercial License**

BY-NC-SA **Creative Commons – Attribution Noncommercial Share Alike License**

GNU-FDL **GNU – Free Documentation License**

Make Your Own Assessment

{ Content Open.Michigan believes can be used, shared, and adapted because it is ineligible for copyright. }

PD-INEL **Public Domain – Ineligible**: Works that are ineligible for copyright protection in the U.S. (17 USC § 102(b)) *laws in your jurisdiction may differ

{ Content Open.Michigan has used under a Fair Use determination. }

FAIR USE **Fair Use**: Use of works that is determined to be Fair consistent with the U.S. Copyright Act. (17 USC § 107) *laws in your jurisdiction may differ

Our determination **DOES NOT** mean that all uses of this 3rd-party content are Fair Uses and we **DO NOT** guarantee that your use of the content is Fair.

To use this content you should **do your own independent analysis** to determine whether or not your use will be Fair.

ICD Connection:
Living with an implantable cardioverter defibrillator

A Collection of Patient & Family Stories

Helen McFarland, RN

Foreword by Frank Pelosi, Jr., MD

Cover Design by Donna Wilkin

Published by MPublishing, University of Michigan Library

ISBN-13: 978-1-60785-274-2

DEDICATION

This book is dedicated to all the patients and family members I have had the privilege and honor to care for during my years as a cardiology nurse. In some way, you have helped me to become a better nurse and a better person. Through you, I am continuously reminded to appreciate the strength and resiliency of the human spirit.

CONTENTS

FOREWORD

If you are reading this book, your life or the life of someone you know has likely changed or is about to change. The stories you will read are about change. These lives have changed with a heartbeat--something we take for granted every second of every day. These stories are about a group of courageous individuals who have received a remarkable technology called an implantable cardioverter defibrillator or ICD. These are stories of suffering, grace, renewal and wisdom.

What is an ICD? It is a device smaller than a deck of cards that is implanted under the skin to treat life-threatening heart rhythms that can lead to sudden cardiac arrest. As the name implies, sudden cardiac arrest results in a sudden halt of one's normal heartbeat that can lead to death in a matter of seconds. An ICD functions like a paramedic implanted in the body, monitoring every heartbeat and delivering treatments if a life-threatening heart rhythm is detected. One of those treatments is an internalized shock that, though it lasts fractions of a second, can be quite painful. The ICD has evolved from a technology requiring open-heart surgery to one that involves little more than a 2-inch incision and local anesthetic.

Having a serious heart condition that needs a permanently implanted artificial device that shocks you is a frightening prospect. The men and women in this book have received this sobering news at an unfairly young age. Most of them have received this news when they otherwise feel very normal--even vibrant. They must deal with life issues that most of us face only decades later; issues with a profound impact that extends to their parents, spouses, children, and friends.

As you read these stories, I would like you to reflect on a few themes. First, these individuals have endured a period of both physical and emotional suffering. Their mind is pummeled with questions that at first have no answers: What if I get a shock? What if the device does NOT work? What can I do? What can't I do? Am I broken? Who will love me like this? How long will I live? How will I die? The control and self-reliance that they once had now seem lost as they enter into a period of profound weakness, anxiety, and perhaps depression.

During this time of suffering and weakness, a remarkable process begins. The person avails themselves to the perfected grace of others. Almost miraculously, the person sees the uncloaked love and caring of family, friends, and even strangers. Gradually, but certainly, they find that an acquaintance who shares their plight becomes a dear friend, a boyfriend becomes a soul mate, and doctors and nurses become brothers in arms. They now cling to a faith that had once been only a companion. A touch of the hand, a caring smile, or a passing comment becomes a lifeline as these individuals rise from their seemingly drowning darkness.

From this grace, renewal begins. In these stories, a new person is reborn. For one young man, fear is replaced by fortitude to compete in collegiate athletics. For another, it is the resolve to find her dream job. For another woman, it is the discovery of someone who will truly love her for who she is, ICD and all.

The last few paragraphs of each of these stories describe the lessons these men and women have learned and advice they give to others. Wisdom is defined as understanding the deeper meaning of our world's realities. What remarkable wisdom they have gained from their experience! To paraphrase a popular song, they have become better friends and spouses; they love deeper and speak sweeter. They have learned lessons that all of us should heed: that each day of life is a precious gift; that true strength lies in a reliance beyond ourselves; and that our success will not be measured by titles or bank accounts, but by how we love, forgive, and care for one another.

I would like to thank these brave men and women for sharing their lives with us. They have transformed their personal tragedy into triumph simply by carrying on with their lives. They are living inspirations to their families, friends and the medical professionals that are charged with their care. I know that by reading this book, you will be changed. I know that I have.

Frank Pelosi, Jr., MD, FACC, FHRS
Director, Cardiac Electrophysiology Fellowship
University of Michigan Medical School

PREFACE

Each year at the University of Michigan "Young ICD Connection Conference," ICD recipients and family members courageously and generously stand in front of a crowded room and share their unique stories of living life with an ICD or supporting a loved one who has an ICD. The room is quiet as the attendees, ICD recipients themselves or family members, connect and identify with the range of emotions the speakers experience as they unveil their personal stories. Year after year, the feedback from the attendees can be summed up in a realization that they are not alone in their concerns, their worries, and their fears.

The inspiration for this book came from this particular session at our conference. Connecting with others who are experiencing similar situations can help us find encouragement and hope in our own situation. I would like to sincerely thank Kathryn, Colin and Ryan, Erika and Bryan, Phyllis, Terri, Brett, Renee, Lisa, Michelle and Alvaro who agreed to tell their very personal stories in this book. Each of them wanted to tell their story in the hope that it may help others who are finding ways to cope with similar life changing experiences.

As a nurse who has provided follow-up care to ICD recipients for a number of years, I was interested in publishing a book that provided an outlet for the voice of the ICD recipient and family members. There are numerous books and articles available from a medical standpoint about ICD implantation. However, no medical book could help me to understand the impact an ICD could have on someone's life. This I learned from listening to my patients. I'm hoping this book will be a resource for medical staff taking care of cardiac and device patients and allow them to gain insight into the patients' concerns by listening to the patients' voices in this book.

I would like to acknowledge and thank Jasna Markovac, PhD, Senior Advisor of Publishing and Related Business Development at the University of Michigan Medical School for her expertise and guidance with this project. Jasna listened and led the way to making my vision of this book a reality.

Lastly, I would like to thank the planning committee of the University of Michigan "Young ICD Connection Conference." The committee is made up of staff from the University of Michigan Congenital Heart Center and Cardiovascular Center. These committee members take great care each year to maintain a program that provides support and education for ICD recipients and their families and to do this in a festive manner.

Celeste Balas, RN
David Bradley, MD
Brynn Dechert-Crooks, NP
Susan Duart-Digon, LMSW
Eric Good, DO
Laura Horwood, NP
Staci Kaczor, NP
Martin LaPage, MD
Shannon Laursen, NP
Gerald Serwer, MD
Dan Bochinski, RN
Theresa Davidson, RN
Macdonald Dick, MD
Carey Fette, RN
Laurie Hill, RN
Frank Pelosi, MD
Mary Kozonis, MSW
Erika Laszlo
Corey Ryder, CVT
Barb Shaltis, LMSW

Roxanne Smith
Donna Wilkin

Rachel Thompson, CCLS

Brian Boron – Medtronic, Inc.
David Thompson – Medtronic, Inc.

Helen McFarland, RN
University of Michigan Hospital
August, 2012

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)