Esophageal Cancer:

Real-Life Stories from Patients and Families



Edited by
Ellen R. Abramson

Red/White Iris Cover artwork by Vincent Maiorana, Reprinted with permission

Cover design by Aki Yao Learning Design & Publishing Medical School Information Services

Produced by Learning Design & Publishing Medical School Information Services

> Published by Michigan Publishing University of Michigan Library

© 2016 The Regents of the University of Michigan

All rights reserved.

ISBN: 978-1-60785-357-2

DEDICATION

With heartfelt thanks to Dr. Mark Orringer whose care, leadership and innovations have meant so much to so many.

CONTENTS

Dedication

Preface

Acknowledgements

Foreword

1.	Why The Esophagectomy Support Group Is So Important To Me, by Lori Flint	1
2.	In Sickness and In Health, by Andy A.	5
3.	The New Normal, by Anne A.	ç
4.	Know That Life Is A Gift, by Clare L.	13
5.	Tales From The Blindside, by Connie L.	19
6.	My Path To Surviving and Thriving, by John K.	37
7.	Each New Day Is A Blessing, by Ken S.	43
8.	My Esophagectomy Story, by Paul E.	55
9.	My Toughest Marathon, by Peter H.	61
10.	Surviving Esophageal Cancer, by Russ P.	67
11.	My Journey: Esophageal Cancer to Transhiatal Esophagectomy, ("THE"), by Stephen P.	71

12.	Esophagectomy Story, by Vincent M.	77
13.	My Experience With The Esophagectomy Support Group,by Tiffany Staal	85
	Biography of Mark Orringer, M.D.	89
	Resources	91
	About the Editor	93

PREFACE

For the past eleven years, I have worked as a fundraiser for the University of Michigan Health System. Before that, I worked as a fundraiser for the American Red Cross, and earlier yet for the Ross School of Business at the University of Michigan. In all, I have been a development officer for twenty years. To many people, the idea of asking for money is terrifying. They are afraid of doing it wrong, embarrassing themselves, being perceived as rude or inappropriate. And they are afraid of rejection. I, too, have felt all those fears.

I have learned, and I encourage colleagues and friends who would like to be able to ask for support to remember, that we are not asking for ourselves. We are not even asking for the University of Michigan Health System or the other organizations we serve. We are asking on behalf of the people who will benefit from the support. I am asking on behalf of the patients and families who will benefit from the medical research that philanthropy makes possible. I am asking on behalf of the patients who will be cared for by doctors who received scholarships or whose education was enriched through private support.

When I began fundraising for U-M Thoracic Surgery, I began to hear stories – stories of esophageal cancer patients who survived, stories of husbands and wives whose spouses had passed away but who were grateful for the extra several months or several years which their care at U-M Thoracic Surgery had made possible. I realized that these patients and families – and people like them – were the people for whom I was asking for support.

I became aware of the Esophagectomy Support Group and was warmly welcomed by the group and given the opportunity to attend several meetings. I shared with them the idea of this book - a compilation of stories of patients who had undergone esophagectomy surgery. I offered two purposes for the creation of this book. One was the opportunity to have an additional helpful resource for esophageal cancer patients, and their families, who were facing this surgery. The other was the opportunity to dedicate this

book to Dr. Mark Orringer, the surgeon for many of these patients, and someone to whom they are all so deeply grateful.

It is a great privilege to help people make a meaningful difference in the lives of others, in a way that is also deeply meaningful to them. That's the way I look at my fundraising, and that's the way I look at this book. I hope that there will be many people for whom this book is deeply meaningful.

Ellen R. Abramson Associate Director of Development University of Michigan Health System

If you are interested in knowing how you can help advance research on esophageal cancer and other thoracic cancers and conditions, please contact the University of Michigan Health System Office of Medical Development at (734) 998-7705.

ACKNOWLEDGMENTS

Thank you to Dr. Andrew Chang, the John Alexander Distinguished Professor of Thoracic Surgery, and Head of Thoracic Surgery at the University of Michigan, for his support and partnership on this project.

I am very grateful to Lori Flint, RN, and Tiffany Staal, RN, for their enthusiasm for this book idea, and their kindness in reaching out to members of the Esophagectomy Support Group.

A special thank you goes to Jasna Markovac, Senior Director, Learning Design and Publishing, Medical School Information Services at the University of Michigan. It was Jasna who suggested the idea for this book when I shared with her about the remarkable courage of our esophagectomy patients and their families in the face of tremendous challenge. I am grateful for Jasna connecting me with her colleague Karen Kost, Associate Publisher. Karen provided the step-by-step guidance and support that transformed a series of stories into a book. I have enjoyed the process of creating this book, and know that it would not have happened without the services provided by Jasna, Karen, and MSIS Learning Design and Publishing.

Finally, my most profound thanks go to the authors whose stories appear in this book. I am deeply grateful for their courage in writing these stories and their generosity in sharing them.

Ellen R. Abramson

FOREWORD

"The same way, every day" is a mantra heard frequently in the operating rooms and patient wards at our hospital as a reminder by my mentor and colleague, Mark Orringer, MD, about the importance of being vigilant and attentive to the care of our patients, particularly those who have undergone an esophagectomy. Esophageal cancer is a devastating diagnosis for which patients often need chemotherapy, radiation as well as surgical treatment. During an esophagectomy, removing the cancer requires removal of the majority of the esophagus, the fibromuscular tube through which food passes before entering the stomach. In order to restore swallowing, the stomach is reconfigured into a tube that is repositioned through the chest and sutured to the remaining esophagus.

Each story in this collection describes the courage and strength that these patients and their families exhibit following an esophagectomy when a patient must learn to adapt to changes in his or her ability to eat, to handle side effects such as nausea, abdominal pain, regurgitation and dumping syndrome.

As you read these stories, please consider that these individuals have endured considerable physical pain and emotional anguish. At the time of diagnosis, patients might experience disbelief and shock. After a sometimes-bewildering array of testing and consultation, after completing treatment and getting through their operation, patients may have numerous questions: Will the cancer return? Will further treatment be needed? How will I be able to eat? Such questions and many more reflect the potential loss of control and loss of independence that we all might experience in similar situations.

In 2002, Lori Flint, RN, started our esophagectomy support group to provide a venue where our patients and their families could work through these questions with others who have had to address similar concerns. As families, friends and even strangers provide their care and support, patients begin a remarkable transformation into recovery.

Esophageal Cancer: Real-Life Stories from Patients and Families

We are indebted to these men and women and their families for sharing their life stories.

Andrew C. Chang, M.D.
John Alexander Distinguished Professor of Thoracic Surgery
Associate Professor of Surgery and Section Head
University of Michigan Medical School