
With Every Breath: A Lung Cancer Guidebook

With Every Breath: A Lung Cancer Guidebook

Tina M. St. John, M.D.

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Important Note to All Readers

I hope you find a great deal of useful information in *With Every Breath: A Lung Cancer Guidebook*. However, *With Every Breath: A Lung Cancer Guidebook* is for informational purposes only.

The information in this book is not a substitute for professional medical advice and care. It is not intended to be nor should it be used as a substitute for individual medical care from a trained medical professional.

All readers are strongly urged and advised to consult a trained medical professional before acting on any of the information in this book. Lung cancer treatment is a complicated and highly specialized field. Treatment plans must be individualized on a case-by-case basis, taking into account the latest developments in the field of lung cancer.

The fact that a particular treatment, supplement, product, or practice is discussed in this book does not mean it is recommended for any individual. Each person seeking to use any of the treatments, supplements, products, or practices in the book should first consult with a trained medical professional.

Similarly, the fact that an organization, Internet site, book, videotape, DVD, or other product is mentioned in this book should not be interpreted as an implication that the author endorses the products, information, services, or information.

Dedication

With Every Breath: A Lung Cancer Guidebook is dedicated to all the courageous people who face the challenges of lung cancer – past, present, and future.

This book is also lovingly dedicated to all those who have died of lung cancer – our mothers, fathers, husbands, wives, aunts, uncles, cousins, grandmothers, grandfathers, friends, and neighbors. Their presence and spirit remain in the hearts of their loved ones, and of all people who work as lung cancer advocates.

Preface

There are times in life when one questions whether there is any order or justice in the world. For me, this happened when my 40-year old, healthy, vibrant husband was diagnosed with stage IV non-small cell lung cancer. We were happily married and had just celebrated our daughter Hope's second birthday. Everything seemed 'right' with the world, except for one seemingly minor problem – my husband had a cough that wouldn't go away. After several weeks, I suggested a chest x-ray. I remember distinctly that I was setting the table for dinner when he came home on the last day B.C. (before cancer). I set down a plate and glanced up while greeting him, completely unprepared for what was about to happen. When I looked up, I saw something in his eyes I had never seen before. And in that instant, I knew our lives had changed forever.

The next 15 months were filled with many challenges. There were many tears, but also much laughter. There was sadness, but also great joy. There was pain, but also abundant happiness. There were treatments and procedures and appointments. There were birthday parties and anniversary cakes and Christmas presents. In the end, my husband and my daughter's Daddy died – but not before having lived many happy, joyful days between his diagnosis and his death.

For a time after my husband's death, it seemed all order had disappeared from the lives of my daughter and me. That was five years ago, and much has happened since those days. We have found our way back to celebrating life – but now, we do so with a deeper sense of gratitude for each day. The joy my family shared during the last 15 months of my husband's life provided us with many delightful memories that live in our hearts and continue to bring my daughter and me much happiness.

One of the most difficult and yet changeable circumstances of dealing with lung cancer is a lack of knowledge. It can be very intimidating to be faced with potentially life-changing decisions while feeling you do not have the information you need to choose wisely. Filling that gap by providing you with medical and practical information is what this book is all about. In writing this book and deciding what to include, I have relied not only on my professional background, but also on my personal experiences, my husband's experiences, and the experiences of many friends I have met over the years who have also faced the challenges of lung cancer. ***With Every Breath: A Lung Cancer Guidebook*** is written for people who have recently been diagnosed with lung cancer and their loved ones. Living with lung cancer is a family matter. The person with the disease and all his or her loved ones are affected by the disease in one way or another.

I am genuinely honored to have an opportunity to try to do something useful for the lung cancer community. Writing this book allowed me to turn the experiences of my family and other families that have been affected by lung cancer into something that will hopefully benefit others. Writing this book has been a labor of love. It is my sincere hope that the information provided in these pages will bring you not only factual knowledge, but also peace of mind. If you find just one thing in this book that contributes to your well-being, the goal of writing this book will have been accomplished.

To Andrew L. St. John, thank you for teaching me what it means to truly live each and every day to its fullest. Thank you for showing me the precious joy of a single moment. And thank you for all the gentle lessons about what it means to truly love someone. Your love and laughter live on – always.

To my beloved daughter, Hope, you are my greatest teacher. You are both my Hope and my hope.

To you, dear reader, I wish you and your loved ones strength for your journey, hope to light your path, peace to fill your soul, and love to warm your heart.

Tina M. St. John, M.D.

Acknowledgements and Thanks

It is a truly humbling experience to sit and think of all the people I must thank for making *With Every Breath: A Lung Cancer Guidebook* possible. So please bear with me — there are many people to whom I need to express my gratitude.

I am profoundly thankful to all the people living with lung cancer and their loved ones who contributed to *With Every Breath: A Lung Cancer Guidebook* by sharing their thoughts, experiences, and wisdom. Your voices and thoughts enrich this book immeasurably. You have given these pages heart. Thank you for your generosity, candor, and kindness. You are truly an inspiration to me as I am sure you are to many others.

Linda J. Bird, I am deeply grateful for your ideas and inspiration in designing the book cover. It symbolizes hope and peace, two of the most important messages of the book. Cindy Langhorne and Jan Healy formerly of the Alliance for Lung Cancer Advocacy, Support, and Education, thank you your kind personal support.

To my loved ones, all family in my heart (and you know who you are), thank you for your steadfast love, support, and confidence in me. You are part of this effort, too, for without you, I'm not sure I would have come to a place to be able to put words like these down on paper. Thank you for all you are, and for sharing that so generously with Hope and me.

To my daughter, Hope, you are the best, Honey Girl. Thank you for being so patient when Mom was working on the book. But more importantly, thank you for being such a wonderful you. I want to be just like you when I grow up!

I am also deeply grateful to the people listed below for thoughtfully and carefully reviewing *With Every Breath: A Lung Cancer Guidebook*, in whole or in part. Your input and comments have been invaluable. Thank you for sharing your time and expertise for the benefit of all those facing the challenges of living with lung cancer.

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Introduction

With Every Breath: A Lung Cancer Guidebook is for you. This book was written to provide you with information to help you live as well as possible with lung cancer. Regardless of your prognosis, you can choose your attitudes and responses to your disease.

Learning about lung cancer and its treatments will help you and your loved ones make informed decisions about your care and your life. As an informed health care consumer, you will be in the best possible position to find quality care. You will be prepared to plan for the future. You will be empowered to have the best quality of life possible. Information can help you find your own way of living with lung cancer and making treatment decisions that suit your personality and preferences.

There are many medical terms included in this book. While medical terminology can be intimidating because it is unfamiliar, learning medical terms will help you better communicate with your health care providers. To make the process of becoming familiar with medical terms easier, they appear in *italics* the first time they are used in a chapter. Definitions of these words appear in the text and also in the *Glossary* at the end of the book.

A unique feature of this book is the personal comments from people with lung cancer and their loved ones that occur throughout the text. Their comments reflect their personal thoughts and experiences. I am deeply indebted to all those who have shared their unique experiences and perspectives for your benefit.

One of the goals of this book is to help you find the assistance you need to fulfill your health care and personal needs. Numerous references are included throughout the text that are intended to help you find the information and resources you need. There is also a *Resource Directory* section at the end of the book to supplement the information provided in the text.

I hope you find a great deal of useful information in *With Every Breath: A Lung Cancer Guidebook*. However, **the information in this book is not a substitute for professional medical advice and care.** Lung cancer treatment is a complicated and highly specialized field. Treatment plans must be individualized on a case-by-case basis, taking into account the unique manifestations of the disease in each person and his or her other medical problems. I urge you to seek advice from your personal doctor and cancer care professionals. You have the right to seek the advice of as many professionals as you wish.

As you read *With Every Breath: A Lung Cancer Guidebook*, I hope you feel a sense of support from all the people who contributed their time and expertise to this book. The people who worked on this book did so because they are committed to helping people faced with the challenge of lung cancer.

I sincerely hope the information in this book contributes to your health, well-being, and peace of mind. I wish you healing and wellness.