



*I Can't Hear
the Music
Anymore*

*One Family's Journey with
Frontotemporal
Dementia*

2nd Edition

by

Linda Anne Bentz Parsons

Douglas Parsons' Sister
Wanda C. Reygaert, PhD.

“So many books on Alzheimer’s and dementias emphasize the how-tos on medical care and caregiving for these diseases, and although this book contains some of this same type of information; its emphasis is on the patient and the patient’s family.

This is an honest and heartfelt story of one family’s journey through the trials of dealing with dementia; about losing a loved one long before the disease claims their life.

It is our family’s desire that this book be a blessing and help to those who now, or will someday, find themselves on this same difficult journey.”

Pam Schuellerman, Executive Director of
Alzheimer’s Association,
Greater East Ohio Chapter

“This volume is a wonderful, quick read; it gives awareness to the anomalies of frontotemporal dementia and the importance of pursuing accurate diagnosis and treatment. The Parsons family is generous to share their journey with courage and candor. People who are caregivers for persons with dementia will identify with and benefit from hearing their story

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FOREWORD

By Dr. Peter J. Whitehouse, M.D. Ph.D.

Many, including the author, Linda Anne Bentz Parsons, her husband Doug, who is my patient, and their four children believe, as I do, that music provides more than pleasure during the journey through life. Songs lift the human spirit, connect us to community, and allow us to transcend our individual lives. Doug C. Parsons, for reasons that we will never understand, is afflicted by what medicine calls frontotemporal dementia. This illness robbed him of some of the joys of music.

Frontotemporal dementia (or FTD as it is abbreviated) is characterized by progressive loss of thinking abilities. Dementia is the general medical category that means a loss of more than one thinking ability. In FTD, someone with normal intelligence begins a gradual decline into a state of increasing dependency on others, with the symptoms and signs varying considerably amongst different patients. The principal problem lies in a complex area of human thinking

and feeling called “executive functions.” To better understand what this is, picture the CEO of a company. He or she must set the goals, develop a plan, motivate others, assess the success of the plan, and make changes in response to the external environment. On an individual level, all human beings have these abilities to varying degrees and while these cognitive capabilities are poorly understood, we know they are particularly associated with the front parts of the brain (frontal lobe) and in addition, to a degree, the parts behind our ear (temporal lobe). Those experiencing FTD can have their emotions disrupted as well as their thinking, so that patients and their families may experience changes in personality and difficulties relating to other people. Sometimes they can behave inappropriately in public, which is stressing to everyone.

FTD is one cause of what doctors called dementia. Labels can be helpful, but they can also be frightening and distort the individual experiences with neurological illness. Also experts do not always agree on how to diagnose FTD, even when brain tissues are available to examine under the microscope. Ultimately every person’s journey through a

condition like FTD is unique and so much of that journey depends on family and community. Quality of life can be dramatically impaired by one's environment; conversely, new sources of hope and joy can be found.

Another more common form of dementia, often compared to FTD, is so-called Alzheimer's disease or AD. It is said that AD is the most common cause of dementia. In actual fact, AD is probably many conditions and is intimately related to normal aging. Clinically and biologically there is much variability in the brains and behaviors of people that we currently label with this term. Yet all of us suffer some form of memory or other thinking impairment as we age. The ability to multi-task is often affected. This ability to pay attention to what's going on in our environment is essential to performing activities of daily living, ranging from simple tasks like getting dressed to complex tasks like using our computers. Many patients with so-called AD will have some executive dysfunction. Patients with FTD have even more difficulty with multitasking, setting goals and implementing plans. FTD often affects people at earlier ages than most forms of AD,

causing special individual and family stresses, particularly of a financial nature. Linda does us a great service by describing the symptoms that Doug has experienced.

Linda also vividly relays the critical importance of faith. Many in our secular world have a faith in science, i.e. that we will learn to fix problems like FTD. Having worked in the field for a quarter of a century, I am aware of the complexities of the problems that we are trying to solve biologically. Scientists and clinicians cannot even agree on the best ways to define and evaluate FTD. I am also aware of the distortions in people's hopes and expectations that hype created by excessively enthusiastic scientists or overly profit conscious companies can create. We have put too much faith in technological fixes that often turn out to be expensive, unable to solve the problem we wanted fixed, and a source of additional problems, for example environmental damage.

Other sources of faith are many and need to be enhanced in our spiritually impoverished world. The Christian faith serves to comfort the Parsons family. Yet there are many forms of Christianity and many other

religions that have helped others cope courageously with adversity. Many who are agnostics or atheists find faith in the human spirit. Let us not be intolerant of the many ways that human beings find solace in the world and a sense of meaning beyond themselves.

I commend the Parsons family for finding their faith amongst the tragedy that FTD can bring to a family. In writing this book Linda has allowed us to see both the sadness and tragedy and the joy and hope of rising to meet the challenges of brain dysfunction.

PREFACE

By Dr. Andrew P. Stalker, M.D.

There are many neurological diseases that create great challenges for those affected and their families. As a general neurologist, I've treated patients with many different diseases, and I've seen my patients and their families deal with many difficulties. There is no disease that I have seen that creates greater challenges for a patient or has a greater impact on a patient's family than dementia in general, and frontotemporal dementia (FTD) in particular.

When a person develops dementia, the usual family dynamic is often reversed. So often the person, who has provided wisdom, support, care, and guidance for decades, is now the one who needs these very things from others. A father who for years has been the primary driver may now rely on his wife and children to drive him around. A mother whose daughters had for years come to her for advice may now need to have those daughters make important decisions for her. Families struggle with this

reversal of roles. I often spend more time during office visits discussing practical solutions to these difficult challenges than I spend discussing medications or testing results.

In some ways FTD affects each afflicted person differently, as each person is a unique individual. However, there are many common situations that arise for patients and their families. So often families feel lost and unsure what to do. This book is a wonderful resource for those families, telling the story of Doug Parsons and his family. They share the confusion and uncertainty they faced during the initial years before Doug was diagnosed. They share the struggles and challenges that they faced when new FTD symptoms arose. They share how they found strength through their faith, love, family, and friends

. Hopefully many others with FTD and their families can read this book and come away with a better understanding of the challenges that they may face and with better preparation for handling the difficulties that will arise. Thank you Linda for writing down the Parsons

family's story so that many others can learn and have a better understanding for it.

A MESSAGE FROM THE AUTHOR

I wrote this book for all those who are taking a journey with frontotemporal dementia. This may be the person who has it, a spouse who has to help take care of a mate who has been diagnosed with it or a family member or friend who would like to know how to help those who have FTD.

Whatever your reason is for wanting to know more about the effects of this disease, I hope that this book may give you some insight into some of the problems that may be faced. May it also be a guide for those who have not chosen to take this journey, but find themselves on it anyways.

This book is not meant to be a medical handbook about FTD, but a resource and an encouragement to help people get through an especially difficult time in their lives.

May God grant you faith, hope and love, and the ability to look beyond yourself for strength to live each day to the fullest.

Linda Anne Bentz Parsons

Dedication

I would like to dedicate this book to my husband, Douglas C. Parsons, who has been and remains my inspiration for telling this story. Since his diagnosis with frontotemporal dementia, our whole family has been on this journey together.

I would also like to dedicate it to our children: Steven, James (Elizabeth), and David Parsons, and our daughter, Laura Parsons Lytle. David and Laura live with us and help us faithfully with their Dad's care every day. Each of our children is special and is very involved with our lives.

I am thankful for our friend Thomas White and all of his efforts toward the editing of this book.

Without all of their assistance and concern, we would not be able to complete this journey.

I love each one of you and thank God for you!

Linda Parsons