### A.M.D.G.

# THE PEACE WITH DEMENTIA ROSARY EDUCATION **†** INTENTIONS **†** COMMUNITY

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# MATTHEW ESTRADE, MA, MBA

DementiaRosary.com Peace with Dementia Press

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*Imprimatur* Most Reverend Gregory M. Aymond Archbishop of New Orleans June 6, 2019\* \*Granted after printing

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# DEDICATION

To Mom, sole care partner to my grandfather who had dementia.

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# Foreword

Growing up Catholic, the Rosary was an ever-present fixture in my life. As early as 1st Grade, we were learning about the Rosary and how to correctly pray the Rosary. I still have the first Rosary I ever received on the day of my First Communion and I also have a Rosary blessed by Pope John-Paul II.

As a child, I remember my Mother, the most devout Catholic (in my opinion) I've ever known, going to daily Mass at St. Agnes Church, praying the Rosary before Mass started. My Grandparents would sit in their bedroom each night at 8pm and listen to the radio broadcast of the Rosary. I'd hear my Grandmother's sweet voice reciting the *Hail Marys, Our Fathers and Glory Bes* in English and my Grandfather reciting those same prayers in Cajun French. Although he spoke English (with a strong Cajun accent) he learned how to pray the Rosary from his parents who spoke Cajun French. In hindsight, I wish I would've paid more attention and learned the Cajun French version of the Rosary.

So, when I first met Matt Estrade at a conference in Lake Lanier, Georgia in April 2018 and learned he was from my hometown of New Orleans, LA, was working at Ochsner Hospital (a place I knew very well), and was writing a book, not just about the Rosary but a "Dementia Rosary," I was very intrigued.

You see, in 2014 at the age of 54, I was diagnosed with Alzheimer's Disease. My Great-Grandmother, Grandfather, and Mother, whom I referenced earlier, all died with Alzheimer's Disease and my Father died with Vascular Dementia. *The Peace with Dementia Rosary* that Matt created is so relevant,

so present, so relatable. So, when he asked me to write the foreword for his book, I felt both honored and proud, knowing I would have the strength and knowledge of my Mother and Grandparents guiding me.

As I write this, I glance up and notice on one of the shelves of my bookcase, a Rosary I draped over a statue of the Blessed Mother, a statue my Mother kept in a curio cabinet. The Rosary is purple (the color used to represent Alzheimer's Disease) and the decades of the Rosary, instead of having the normal beads, are hearts. This was gifted to me during my marriage to Shannon. She knew of my deep Catholic roots and Catholic faith. I don't remember the occasion for which she gave it to me, but what I do remember is the comfort it gave to me then and still does today.

The Rosary is not just prayers said over and over again. It is a combined form of prayer and meditation that has been around several hundred years. Before the beads were placed on a small chain or rope, pebbles were carried around in small pouches so whoever was praying could keep track of the number of prayers being said. Later, small pieces of wood were placed on a string to easily keep track.

Matt has taken the Rosary to a different level. He has combined the twenty decades of the four Holy Mysteries with specific prayers for individuals living with Dementia, for their Care Partners, for their families, and more. It's not changing the meaning of the Rosary, but rather directing the prayers towards the world of Dementia. Trust me, we can all use a prayer or two to help us through each day.

I know I spoke of my Catholic Faith at the beginning of this piece, however, you don't need to be Catholic to pray the Rosary. That's the beauty of this book. Matt guides you through

Foreword

the process of how to pray the Rosary. It's a blueprint for you to utilize.

My hope is that one day, there will be an Alzheimer's Survivor, a Parkinson's Survivor, an FTD Survivor, a Vascular Dementia Survivor or a Survivor of any type of Dementia. Until then, your prayers are welcome. We would ALL be appreciative and on a personal note, I WHOLEHEARTEDLY THANK YOU!

#### **Brian LeBlanc**

International Alzheimer's Advocate

"I Have Alzheimer's BUT . . . it DOESN'T have ME!" https://abitofbriansbrilliance.com/

June 28, 2018 Pensacola, Florida

Sign up for email updates at www.DementiaRosary.com and receive 'A Novena to St. John the Evangelist, Patron Saint of Care Parters/Caregivers.'

The Peace With Dementia Rosary

# Thank you for joining our community praying *The Peace with Dementia Rosary*.

# Education Intentions Community

By purchasing this book, you are supporting more educational resources like *The Peace with Dementia Podcast, The Peace with Dementia Rosary Blog*, underwriting my research projects like the impact of education on the ambiguous loss of dementia care partners, and expanding the reach of the information through conference presentations. **Most importantly, you are creating a community of families praying for families during a very challenging time.** For all of this, I am very grateful and wish you God's blessings.

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# How to Use This Book

Just like the decades of the Holy Rosary of the Blessed Virgin Mary, which takes us on a journey of joyful, luminous, sorrowful, and glorious moments, so too does the journey of dementia. Although the experience of dementia and dementia care partnering is not exactly the same for all families, there are common themes on each journey that consist of many *ups* and *downs*. The *ups* may be far less common than the *downs* for you, and one purpose of this Rosary is to recognize the current *ups* and increase the *positive moments* on the journey.

*The Peace with Dementia Rosary* will guide you through the traditional Rosary, while offering dementia education and a special prayer request for each decade of *Hail Marys*.

This book is written for persons living with dementia and their care partners. I encourage you to include the person living with dementia in this Rosary whenever possible, even if you are simply sitting with them or holding their hand as you recite the prayers. Persons living with dementia tend to retain long-term memories, such as prayers said throughout their lifetimes. If the prayers, education, or intentions are troublesome for the person living with dementia, say a traditional Rosary with them. Experiment to find the best time of day for them to pray. If they are not interested or grow frustrated in praying at any time, consider praying alone or with a group.

### Education

Each decade offers education on a specific aspect of dementia. The content was created through my experience as a

gerontologist and as a care partner support group facilitator of over 170 sessions (and counting). The appendix of the book contains citations, websites, books, articles, and guide sheets. The education is brief enough to read (or omit) while reciting the Rosary. It is important to remember that each person and family's situation is unique and all of the educational materials may not be applicable to everyone. Common sense should be considered and this book is just the beginning of your education, not a substitute for professional advice.

### Intentions

The intentions found for each decade are based on the aforementioned education and guide our petitions to Mary. If a specific intention does not apply to you, pray for others who need them. You are encouraged to add to the intentions in your recitation of the Rosary.

### Community

As you may already know, there is extreme power in prayer. When we say *The Peace with Dementia Rosary* at home, in a care community, at a dementia-friendly church, or together online, we are creating a community of prayer towards a common cause. Just like the benefits of a support group, we are stronger when we know that we are not alone on this journey with dementia.

### Please visit https://dementiarosary.com for opportunities to:

- Write a specific request on the Dementia Prayer Wall so others can pray for you and your family
- Pray for other families' requests on the Dementia Prayer Wall
- Participate in online recitations of the Rosary

How to Use This Book

- Find or start a *Peace with Dementia Rosary* group in your community
- Sign up for the email list to receive notices on free education (blog articles and podcasts) and premium education (online classes)
- Tell us about your successes in applying the book's lessons and reciting the Rosary

While Catholics pray the Rosary to Mary, that she may bring our intentions to her Son, we welcome all faiths - or even those who are spiritual without a formal religion - to write a dementia prayer request and to pray for other requests. Also feel free to listen or recite the Rosary with us.

# **Bonus Materials**

Everyone loves bonuses, or *lagniappe* as we say in Louisiana! See the appendix to learn how you can receive bonus book materials and future content. It's just another way to thank you for your support.

Remember, the Rosary is not a substitute for professional medical advice or treatment of medical symptoms (pain, infection, fever, etc.) or psychological symptoms such as depression, with which many care partners wrestle.

# THE STRUCTURE OF THE ROSARY

Make the Sign of the Cross

Apostles' Creed Our Father 3 Hail Marys Glory Be

Announce the first specific decade of the daily Mystery *Our Father* 10 *Hail Marys Glory Be Fatima Prayer* (Optional)

Repeat with the remaining 4 decades of the daily Mystery

Hail, Holy Queen Let Us Pray Memorare

St. Dymphna, Patron Saint of brain disorders, please pray for us!

St. John the Evangelist, Patron Saint of care partners, please pray for us!

Make the Sign of the Cross

Amen.

Traditional recitation days: Joyful Mysteries (Mondays, Saturdays) Luminous Mysteries (Thursdays) Sorrowful Mysteries (Tuesdays, Fridays) Glorious Mysteries (Wednesdays, Sundays) This book is available at many retail websites. When you purchase at www.DementiaRosary.com, our ministry receives much more in royalties to support the mission.

# CHAPTER 1

# INTRODUCTION

Sign up for email updates at www.DementiaRosary.com and receive 'A Novena to St. John the Evangelist, Patron Saint of Care Parters/Caregivers.'

The Peace With Dementia Rosary

# What is Dementia?

Dementia is a broad term used to describe a group of chronic symptoms that may include memory impairment disrupting everyday life, diminished judgment, inability to plan, challenges with words and communicating, disorientation of time and place, and other symptoms. While dementia includes a group of common symptoms, irreversible conditions such as Alzheimer's disease (AD), Dementia with Lewy Bodies (DLB), vascular dementia (strokes), mixed dementia, or other diseases are the causes. Sadly, there is no solution to reverse or stop the progression of these dementia types. If the primary cause of a person's dementia is an infection, vitamin deficiency, depression, thyroid condition, or poor sleep, for example, these can potentially be addressed for improvement.

Of all the estimated dementia cases in the U.S., Alzheimer's disease accounts for approximately 5.7 million of these cases and between 60%-80% of all occurrences of dementia. Researchers believe that the remaining cases totaling over 1 million are caused by diseases in the following order: Mixed dementia with AD & vascular dementia (~50%), Dementia with Lewy Bodies (10-20%) solely vascular dementia (~10%), frontotemporal degeneration (~10%), normal pressure hydrocephalus (< 5%), and Parkinson's disease (<1%).<sup>1</sup> Dementia with Lewy Bodies is often confused with Alzheimer's disease.<sup>2,3</sup> There are many similarities between these diseases; however, each one has unique symptoms that offer clues for identifying which ones are causing dementia. It is important to learn about the particular dementia type affecting you or your loved one in order to offer proper treatments and avoid adverse reactions. For example, offering the antipsychotic medication haloperidol (Haldol) to treat hallucinations, which are common with Dementia with Lewy Bodies, can cause irreversible motor skill losses. Similarly, offering anti-parkinsonian drugs can worsen symptoms for this type of dementia.<sup>4</sup> This and other information

Introduction

in this book should be discussed in partnership with your medical team. It is essential that you work with them to obtain a proper, or in dementia cases a probable, diagnosis.

Speaking of a getting a diagnosis, when I write about a diagnosis of dementia in this book, I am referring to a *probable* diagnosis of dementia. This is because only a post mortem autopsy can confirm dementia and the pathology or disease causing it. Medical teams are able to offer a probable diagnosis with certain cogitative assessments, medical tests, and evaluating symptoms.

## Care Partners and Persons Living with Dementia

I am very fond of using the term "care partner" instead of caregiver or caretaker. It describes a two-way relationship – a true partnership - between a care recipient and someone caring for them.<sup>5</sup> In any partnership, both people (or groups) contribute to the relationship, offer feedback, listen, and give respect. The same can be said for the experience of dementia. If the person living with dementia is not contributing to form a partnership, we need to ask ourselves if we are encouraging their contributions and being open to their input. As I will touch upon in this book, to allow our loved one to contribute and offer feedback on their care is to give them a chance to improve their self-dignity. The more that we can take our cues from the person living with dementia, the better we can provide an individualized care plan for an improved guality of life. After all, we are unique individuals and you may agree that we enjoy our lives more when our own preferences are satisfied.

For example, if your loved one exhibits behavioral expressions that frustrate you, perhaps there is an individual need that you would like to address or maybe there is a stressor bothering them that you do not understand. There is a good chance that

CHAPTER 2

# The Joyful Mysteries

The Peace With Dementia Rosary

# First of the Joyful Mysteries

# The Annunciation



And coming to her, he said, "Hail, favored one! The Lord is with you." But she was greatly troubled at what was said and pondered what sort of greeting this might be. Then the angel said to her, "Do not be afraid, Mary, for you have found favor with God. Behold, you will conceive in your womb and bear a son, and you shall name him Jesus.

Luke 1:28-31

# The Probable Diagnosis

It can be frightening to take the first step of seeing your primary care physician when you suspect that you or a loved one may be having memory or other cognitive (brain) changes. After all, what if the doctor finds something wrong? Will my car keys be taken away? Will I have to stop working or doing other activities? These are valid concerns, but all activities do not cease with a diagnosis. Laboratory and cognitive tests can rule out dementia if the symptoms are attributed to an infection, vitamin deficiency, depression, thyroid condition, poor sleep, or other conditions. If Alzheimer's disease or another type of dementia is suspected, this diagnosis, while troubling, could allow the whole family to plan ahead for future services and transitions.<sup>6</sup> Medical professionals may also be impacted with regard to diagnoses. Sometimes doctors, as experienced as they may be, face challenges and discomfort in giving a diagnosis. However, avoiding a diagnosis can present hazards if not addressed.7

Our Lady of the Annunciation, We pray that we have the courage to seek medical advice even when we do not want to think about the possibility of dementia. We pray that care partners can persuade our loved one to attend the medical appointment and that we have strength if there is news we do not wish to hear. We also keep doctors and other medical professionals in our intentions that they communicate a diagnosis with courage, clarity, and sensitivity.

*Our Father* 10 *Hail Marys Glory Be Fatima Prayer*  This book is available at many retail websites. When you purchase at www.DementiaRosary.com, our ministry receives much more in royalties to support the mission.

### APPENDIX A:

# References and Notes

### Abstracts can also be found using the Google Scholar search engine https://scholar.google.com/

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APPENDIX C:

# ARTICLES

# A Worthy Resolution: Visiting a Loved One with Dementia and Their Care

Chances are great that you know someone who either has dementia or is a care partner for a loved one with dementia. Dementia is an "umbrella" or catch-all term to describe a group of chronic symptoms that include memory impairment, poor judgment, disorientation of time and place, behavior changes, challenges in concentrating, and more symptoms. Dementia is caused by a specific disease or combination of diseases such as Alzheimer's disease (most common), Dementia with Lewy Bodies (second most common), vascular dementia (from stokes), frontotemporal degeneration (FTD), Parkinson's, and others.

There is a reason that you may know someone affected by dementia. Of all the estimated dementia cases in the U.S., Alzheimer's disease accounts for approximately 5.7 million of these cases and more living with other forms of dementia (Alzheimer's Association, 2018). It could be a family member, a friend, a neighbor, or a colleague. There are varying stages where you may or may not see clear signs.

The research and experience tell us that when someone is diagnosed with dementia, their world, and the world of their primary care partner, gets smaller as friends and even some family stop coming around. The Peace With Dementia Rosary

# Maintaining Dignity in Dementia

This care partner guide sheet will take you through questions that will assist you in maintaining dignity for your loved one or client living with dementia.

Utilize common sense when completing. This is, of course, a complex topic and depends on many factors, two of those being your loved one's level of impairment/ability and your level of patience/burnout as a care partner.

More common sense...If your loved one is communicating for help, by all means, help them. They may not be able to complete a task, even if you think that they can. Dementia is a cruel syndrome making one thing possible one minute and impossible the next.

This guide sheet is not medical advice and, as always, seek medical advice from your doctor or nurse practitioner.

 Make a list of things that your loved one can still do safely (as many as you can think of). Some of these may require cueing or reminding of the next step. Here are 4 examples to get you started (you can cross-out if needed):

Brush teeth	Cut up food
Use microwave safely	Shave face

# About the Author

Matthew "Matt" Estrade, MA, MBA is a gerontologist and speaker in the Greater New Orleans area. His grandfather had probable Wernicke Korsakoff type dementia in the late 1990s. Matt has dedicated his career to helping families who are experiencing dementia find peace on this challenging journey through education, consulting, and conducting research.

Locally, Matt facilitates a weekly care partner support group for the Council on Aging in St. Tammany Parish through his training and consulting practice Care Partner Mentoring, LLC.

Matt is the host of the Whole Care Network's *Peace with Dementia Podcast,* which seeks to reduce stigma and promote relationship-centered education to persons living with dementia and their care partners. This and other educational outlets blend practical tips and evidence-based research, making it accessible so that families can take action. You can find the podcast here: http://bit.ly/PWDPodcast

He completed a Masters in Gerontology from the University of Louisiana at Monroe and holds a graduate degree from the University of New Orleans and bachelors from Auburn University. For college prep, Matt graduated from Jesuit High School in New Orleans, LA. He has been a certified Dale Carnegie Instructor since 2005.

Matt lives in Covington, Louisiana with his bride and three children. He is a member of the Health Ministry at Mary, Queen of Peace Parish. Matt volunteers as a Cub Scout and Boy Scout leader at Our Lady of the Lake Parish, where he is also in the

The Peace With Dementia Rosary

Knights of Columbus Council 9240. He earned his Eagle Scout award in 1992. Matt is also a member of the Catholic Writers Guild, Gerontological Society of America, and is the Louisiana State Ambassador for the Southern Gerontological Society.

You can reach out to him by emailing Matt@CarePartnerMentoring.com.

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