

A close-up photograph of two hands, one larger and one smaller, clasped together in a supportive grip. The hands are dark-skinned. The background is a soft, out-of-focus gradient of purple and orange.

# Because I Love You

**MY BOOK ABOUT ME**



CAREGIVER SUPPORT  
AND RESOURCES



## CAREGIVER SUPPORT AND RESOURCES

**Caregiver Support and Resources, LLC**  
**Creating a Life Worth Living with Pre-Planning and Team Building**  
[www.caregiversupportandresources.com](http://www.caregiversupportandresources.com)

Hello, my name is Maureen Rulison, the President and Founder of Caregiver Support and Resources, LLC in Clearwater, FL. My career in life-care planning has spanned nearly three decades. My perspectives are also rooted in personal experience as a care partner. So I know the daily realities elders and their care partners face. It's a beautiful journey. Rather, it can be – if you get your plan together and craft a scenario that promises a life worth living, a death with dignity and a harmonious circle of support.

Nearly 10 years ago, my life partner/care partner, Brian LeBlanc, recorded “A Video To My Future Care Partners.” He lives with Alzheimer’s disease and vascular dementia. His goal was rooted in love, providing his family and caregivers with a roadmap to care on his terms. At the time, he was still remarkably cognizant and a renowned public speaker and advocate for persons living with dementia. Brian knew today would come – a day when he would be living in advanced nursing care and unable to clearly communicate his wishes.

In that spirit, I created this book – “Because I Love You: My Book About Me” – to help individuals and families build or improve their life-care plan. Our mission is to build a dedicated team, smoothing the road ahead, filling potential potholes that might lead to crises, and easing the challenge of climbing the mountains that await us. We must plan for both the anticipated and unforeseen. This caregiving resource allows you and the care-partner team to discuss medical care, advocate for spiritual needs, organize financial and legal documents, and prepare for end-of-life.

And so much more! Let’s build a plan for a life worth living.

Yours in compassionate care,

*Maureen Rulison*



**Maureen Rulison, BCPA, CMP**  
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## How this Book Works

Life is an individual odyssey, and recognizing the uniqueness of each person's passage, I reject the notion of "cookie-cutter" life-care plans. As a Board-certified Patient Advocate in the state of Florida, I've crafted thousands of them for people of all walks of life. For so many, the process requires complex processes like Medicaid & VA eligibility planning, living transitions and care coordination.

While these are critical, let's also focus on the simple things that often go overlooked. Let's build a village of support. Together, we form a partnership with the person in need, their primary care partner and extended care partners — both personal and professional. From there we can learn about each team member, document care needs and work toward end-of-life preferences.

### **This book is separated into 4 steps:**

<i>Step 1: Let's Get to Know Each Other</i>	<i>(Page 4)</i>
<i>Step 2: Tools for Living Your Best Life</i>	<i>(Page 21)</i>
<i>Step 3: Taking Care of Those Who Take Care of Us</i>	<i>(Page 38)</i>
<i>Step 4: Final Stages Planning</i>	<i>(Page 50)</i>

Drawing from our extensive network of professionals serving individuals in similar situations, we leverage our knowledge of available resources to craft a care plan tailored to your unique needs. In the end, we'll introduce you to a few of these professionals from Caregiver Support and Resources, LLC's vast referral system.

## **Shall We Get Started?**



# STEP ONE

**Let's Get To Know Each Other**



## Step 1: Let's Get to Know Each Other.

This step isn't just about gathering information. It's about truly understanding you (or the care recipient) beyond medical needs. By delving into personal preferences, relationships and aspirations, we aim to create a holistic roadmap that respects your autonomy and ensures decision-making remains with the individual.

Here at Caregiver Support and Resources, LLC, we lead clients during this step on a series of sessions designed to foster understanding and build a supportive care partner team. We answer your questions while posing our own to unravel the unique threads of your life.

To craft a comprehensive life-care plan, we explore various aspects like:

- **The Basics:** Necessary and pertinent information about you so that your caregiver has access (Page 6)
- **Care Partner Team:** Collecting names and contact information of family, friends and even cherished pets who each play an integral role in a life worth living. (Page 7)
- **Legal Documents:** Reviewing legal documents in collaboration with an attorney, ensuring your wishes are documented and legally sound. (Page 8)
- **Health Information:** Gathering details about your specific diagnosis(es), medications and other treatments, and understanding other nuances of your health from a medical standpoint. (Page 10)
- **Medical Providers:** Compiling information about your medical providers, including names, contact details and their respective specializations. (Page 15)
- **Financial Information:** Detailing your finances to strategize how to fund your care both now and the future, involving meetings with financial advisors. (Page 16)
- **Likes & Dislikes:** Beyond the clinical, we explore your personal preferences, creating a foundation for a video or written "message to my future care partners. (Page 19)

Our shared objective is to extend decision-making autonomy for as long as possible. Should the need arise, we ensure that decisions are made by individuals chosen by you. The aim is for everyone providing support to know you as the complete person you are, transcending the boundaries of your diagnosis(es).

The next few pages provide space to answer questions and provide relevant information.

# The Basics

My legal name: \_\_\_\_\_

I was born in: \_\_\_\_\_

My birthdate: \_\_\_\_\_

My marital status: \_\_\_\_\_

To whom? \_\_\_\_\_

Previous marriages?

To whom? \_\_\_\_\_

Date of marriage: \_\_\_\_\_

Date marriage ended: \_\_\_\_\_

Current living address: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

What was /is your profession? \_\_\_\_\_

Do you have a valid Photo ID? Yes \_\_\_ No \_\_\_ Type: \_\_\_\_\_

Do you have a Social Security card? Yes \_\_\_ No \_\_\_ Number: \_\_\_\_\_

Do you have a Medicare card? Yes \_\_\_ No \_\_\_ Number: \_\_\_\_\_

Do you have other Medical Insurance? Yes \_\_\_ No \_\_\_ Company: \_\_\_\_\_

Prescription Coverage? Yes \_\_\_ No \_\_\_ Company: \_\_\_\_\_

Long Term Care Insurance? Yes \_\_\_ No \_\_\_ Company: \_\_\_\_\_

Did you serve in the Military? Yes \_\_\_ No \_\_\_

Period of Service? \_\_\_\_\_

Branch of Service? \_\_\_\_\_

# Care Partner Team

Who are the people who you want to act as part of your Care Partner Team? Add more names on a separate sheet of paper.

1. (Legal name) \_\_\_\_\_

Relationship to you \_\_\_\_\_

Address: \_\_\_\_\_

Telephone number: \_\_\_\_\_

E-mail Address: \_\_\_\_\_

2. (Legal name) \_\_\_\_\_

Relationship to you \_\_\_\_\_

Address: \_\_\_\_\_

Telephone number: \_\_\_\_\_

E-mail Address: \_\_\_\_\_

3. (Legal name) \_\_\_\_\_

Relationship to you \_\_\_\_\_

Address: \_\_\_\_\_

Telephone number: \_\_\_\_\_

E-mail Address: \_\_\_\_\_

4. (Legal name) \_\_\_\_\_

Relationship to you \_\_\_\_\_

Address: \_\_\_\_\_

Telephone number: \_\_\_\_\_

E-mail Address: \_\_\_\_\_

5. (Legal name) \_\_\_\_\_

Relationship to you \_\_\_\_\_

Address: \_\_\_\_\_

Telephone number: \_\_\_\_\_

E-mail Address: \_\_\_\_\_

# LEGAL

The Elder Law Attorneys that we partner with do Medicaid Planning, with Asset Protection. A general definition of Medicaid planning is any assistance provided to a potential Medicaid applicant in advance of and in preparation for their Medicaid application. Medicaid planning can be as simple as assistance with the collection and preparation of documents or as complicated as a complete restructuring of one's financial assets. What is Asset Protection? Asset protection for the purposes of qualifying for Medicaid involves moving assets out of the name of applicant or changing the asset into a non-countable asset; without creating an uncompensated transfer of assets.

My Power of Attorney: \_\_\_\_\_

Address: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Telephone: \_\_\_\_\_

Email: \_\_\_\_\_

My Healthcare Surrogate \_\_\_\_\_

Address: \_\_\_\_\_  
\_\_\_\_\_

Telephone: \_\_\_\_\_

Email \_\_\_\_\_

I Have A Living Will                      Yes \_\_\_\_\_                      No \_\_\_\_\_

Other Legal Documents I Have: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Where I Keep My Legal Documents: \_\_\_\_\_  
\_\_\_\_\_

I Have A Safety Deposit Box                      Yes       \_\_\_\_\_                      No       \_\_\_\_\_

Where is it? \_\_\_\_\_  
\_\_\_\_\_

My Attorney Is: \_\_\_\_\_

Address: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Telephone: \_\_\_\_\_

Email: \_\_\_\_\_

Other Legal Notes:  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## HEALTH INFORMATION

My full legal name: \_\_\_\_\_

My date of birth is: \_\_\_\_\_

My current address: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

My current telephone number(s): Home: \_\_\_\_\_

Cell: \_\_\_\_\_

My Primary Care Physician's name: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

Telephone Number: \_\_\_\_\_

Cell: \_\_\_\_\_

My Current Medicare is Traditional Medicare #: \_\_\_\_\_

AND I have

A Medicare Supplement Plan through: \_\_\_\_\_

OR

I have a Medicare Advantage Plan through: \_\_\_\_\_

My Social Security Card is kept: \_\_\_\_\_

Where I keep my cards: \_\_\_\_\_

*NOTE: You can make copies or take pictures of the front and back of all cards and provide them to your Power of Attorney and Health Care Surrogate.*

Do you currently need assistance with any of these?

- |  |          |         |
|--|----------|---------|
| Walking (cane, walker, wheelchair)?                  | Yes ____ | No ____ |
| Transferring (getting in and out of bed or a chair)? | Yes ____ | No ____ |
| Preparing meals?                                     | Yes ____ | No ____ |
| Preparing and/or taking your medications?            | Yes ____ | No ____ |
| Toileting?   | Yes ____ | No ____ |
| Finances?  | Yes ____ | No ____ |
| Bathing?   | Yes ____ | No ____ |
| Dressing?  | Yes ____ | No ____ |

Conditions I have been diagnosed with: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## Immunizations:

Against

Date Received

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## Medical Devices:

Type

Date Received

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## Over-the-Counter Medications and/or Supplements:

Name of Medication	Strength and Frequency	Condition Medication is Taken for	Prescribed by	When Taken

Pharmacy: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Telephone: \_\_\_\_\_

Any Other Relevant Medical Notes

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

## Medical Providers

Physician's name & specialty: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Telephone Number: \_\_\_\_\_

Physician's name & specialty: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Telephone number: \_\_\_\_\_

Physician's name & specialty: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Telephone Number: \_\_\_\_\_

Physician's name & specialty: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Telephone Number: \_\_\_\_\_

# FINANCIAL

Where I bank \_\_\_\_\_  
:  
\_\_\_\_\_

My Financial Planner is: \_\_\_\_\_

Telephone: \_\_\_\_\_

Email: \_\_\_\_\_

Address: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

I have life insurance with: \_\_\_\_\_  
\_\_\_\_\_

My homeowner's insurance is with: \_\_\_\_\_  
\_\_\_\_\_

Other financial information:  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Gross Income Sources and Amounts

- Social Security Monthly Amount \$\_\_\_\_\_
- VA Income Monthly Amount \$\_\_\_\_\_
- Pension Monthly Amount \$\_\_\_\_\_
- Income from IRA Monthly Amount \$\_\_\_\_\_
- Dividends Monthly Amount \$\_\_\_\_\_
- Interest income Monthly Amount \$\_\_\_\_\_
- Other Monthly Amount \$\_\_\_\_\_
- Monthly Amount \$\_\_\_\_\_
- Monthly Amount \$\_\_\_\_\_
- Monthly Amount \$\_\_\_\_\_

Assets

- Checking and Savings  
Where? \_\_\_\_\_ Value? \$\_\_\_\_\_
- CDs  
Where? \_\_\_\_\_ Value? \$\_\_\_\_\_
- IRAs  
Where? \_\_\_\_\_ Value? \$\_\_\_\_\_
- Investment Accounts  
Where? \_\_\_\_\_ Value? \$\_\_\_\_\_
- Stock  
Where? \_\_\_\_\_ Value? \$\_\_\_\_\_
- Bonds  
Where? \_\_\_\_\_ Value? \$\_\_\_\_\_
- Life Insurance Policies  
Where? \_\_\_\_\_ Value? \$\_\_\_\_\_
- Properties  
Where? \_\_\_\_\_ Value? \$\_\_\_\_\_
- Motor Vehicle  
Where? \_\_\_\_\_ Value? \$\_\_\_\_\_
- Other  
Where? \_\_\_\_\_ Value? \$\_\_\_\_\_

Obligations

- Mortgage, home equity line of credit, reverse mortgage...  
Where? \_\_\_\_\_ Value? \$ \_\_\_\_\_
- Credit card debt  
Where? \_\_\_\_\_ Value? \$ \_\_\_\_\_
- Loans  
Where? \_\_\_\_\_ Value? \$ \_\_\_\_\_
  
- Insurance premium payments  
Where? \_\_\_\_\_ Value? \$ \_\_\_\_\_
- Property taxes  
Where? \_\_\_\_\_ Value? \$ \_\_\_\_\_
- Other  
Where? \_\_\_\_\_ Value? \$ \_\_\_\_\_

## Likes / Dislikes:

Do you have any pets?

Species: \_\_\_\_\_ Name: \_\_\_\_\_

Species: \_\_\_\_\_ Name: \_\_\_\_\_

Species: \_\_\_\_\_ Name: \_\_\_\_\_

Species: \_\_\_\_\_ Name: \_\_\_\_\_

Name your 3 favorite musical artists.

1. \_\_\_\_\_

2. \_\_\_\_\_

3. \_\_\_\_\_

Name your 3 favorite TV programs.

1. \_\_\_\_\_

2. \_\_\_\_\_

3. \_\_\_\_\_

Name your 3 favorite foods.

1. \_\_\_\_\_

2. \_\_\_\_\_

3. \_\_\_\_\_

Name your 3 favorite movies.

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

Name the three most important goals you have for your life.

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

Tell me three things you enjoy doing.

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_



# STEP TWO

**Tools for Living Your Best Life**



## Step 2: Tools for Living Your Best Life

Here's a vibrant celebration of you as an individual, beyond diagnoses and medical labels. It's a recognition that joy, purpose and spiritual fulfillment are integral aspects of well-being. That's true whether you – or a care recipient – are aging in good health or bad. We aim to preserve the essence of who you are, fostering an environment where your passions, routines, and spiritual/emotional needs are not just acknowledged, but actively nurtured.

Amidst the practicalities of care, we celebrate a part of a well-rounded life-care plan where joy takes center stage. Here's what it entails:

- **Discovering Joy:** We engage in a joyful journey, exploring your interests, whether it's reading, golf, arts and crafts, or the excitement of embracing something new. Factor opportunities in your life-care plan to savor life's pleasures to the best of your abilities. (Page 23)
- **Person-Focused Care:** We discover the profound impact person-focused care (or person-centered care) has on individuals and care-partner teams navigating the journey of aging, illness, and caregiving. This care philosophy embodies the essence of compassion, dignity and respect for the unique identity and autonomy of each individual. (Page 23)
- **Preserving Your Space:** Medical realities and aging can sometimes encroach on personal spaces and routines. Plan to strike a balance where medical necessities don't overshadow familiarity and comfort. (Page 29)
- **Addressing Spiritual Needs:** Whether it's connecting with dementia-welcoming spiritual services, joining home-based groups or exploring online opportunities, this step nurtures this vital aspect of your being. (Page 31)
- **Empowering Advocacy:** Let's explore advocacy for a life worth living – whether through clinical trials, sharing your journey with others or educating communities about living well with your diagnosis. We put you in touch with the right networks. (Page 33)
- **Planning for the Future:** Practical considerations are also part of this step. We explore the viability of Medicaid planning, VA aid and attendance planning, and asset protection. (Page 35)

This step is a commitment to your wholeness. It's an invitation to express your desires. In turn, Caregiver Support and Resources, LLC strives to provide the right tools and life-enriching connections.

The next few pages provide space to answer questions and provide relevant information.

## Discovering Joy

What activities or hobbies currently bring joy and fulfillment to your life?

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Are there any new interests or experiences you would like to explore?

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How can we incorporate your passions and interests into your daily routine?

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Do you have any specific goals related to pursuing activities that bring you joy?

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Are there any barriers or challenges that may prevent you from participating in activities you enjoy? If so, how may we work to overcome them?

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Would you like assistance in discovering new hobbies or interests that align with your preferences and abilities? If so, how would you prefer to be assisted?

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How can we ensure that your life-care plan includes opportunities to savor life's pleasures and maintain a sense of fulfillment?

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Are there any club memberships, resources or support networks you would like to access to enhance your engagement in joyful activities?

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How do you envision incorporating moments of joy and fulfillment into your daily life moving forward?

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## Person-Focused Care

Here's a care philosophy that I've embraced wholeheartedly over decades of both professional and personal experience. Person-focused care, I've found, the most fulfilling journey to a life worth living with dementia – for the individual and everyone involved in their care. So this book, too, follows and promotes this philosophy, pioneered and refined by our good friends at The Eden Alternative, Pulse Center for Patient Safety, and Education and Advocacy (a fellow Board-certified Patient Advocacy organization).

Person-focused care – also known as person-centered care – is grounded in compassion, dignity and respect. It empowers the individual to direct their own care. They know themselves best, after all. Person-focused care acknowledges the unique identity and autonomy of each individual, regardless of their age or health condition. At its heart, this approach emphasizes the importance of honoring the humanity of those receiving care, fostering meaningful connections, and nurturing a sense of dignity and worth.

A strong life-care plan factors care realities and personal preferences well ahead of time, so there can be no ambiguity or confusion when the individual may no longer have the capacity to advocate for themselves. As we know, dementia is a thief. It cruelly steals memory and cognition until there's nothing left. There WILL come a time when speaking up for oneself is no longer possible. So planning ahead and getting all of these needs and desires in order is critical.

Even language plays a pivotal role in person-focused care, shaping perceptions, attitudes and interactions within caregiving settings. By choosing words and phrases that uplift rather than diminish, caregivers can create an environment that values the individuality and inherent worth of each person. In this section of the book, we delve into the significance of person-focused language and its ability to enhance the caregiving experience for both caregivers and care recipients. As we explore the principles and practices of person-focused care and language, the following series of questions will invite you to reflect.

What aspects of your daily life bring you joy and fulfillment? How can these be incorporated into your care plan to enhance your well-being?

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Reflecting on your unique identity and preferences, what values and beliefs are important to you. How must they be respected and upheld by your care partners?

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In what ways do you envision maintaining your sense of autonomy and independence as you receive care? How can your care partners support you in achieving these goals?

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Consider the language used by your care partners and healthcare professionals. How do certain words or phrases make you feel, and are there any adjustments that must be made in the way you are addressed and spoken to?

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How do you prefer to be addressed and communicated with? Are there any communication strategies that work best for care partners to understand how you think and feel? Similarly, which communication strategies would help you to understand how your care partner(s)' feelings and needs?

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What specific work, activities or hobbies bring you comfort and a sense of purpose? How can these be integrated into your daily routine to promote your overall well-being?

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Reflecting on your past experiences and achievements, what milestones or accomplishments are most meaningful to you? How can your care partners honor and celebrate your life and achievements?

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Consider your spiritual and cultural beliefs. How do these aspects of your identity influence your care preferences, and how can your care partners accommodate these beliefs in your life-care plan?

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## Preserving Your Space

Which aspects of your personal space and daily routines are most important to you?

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How have medical necessities and diagnoses impacted your living environment and daily routines?

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Are there specific adjustments or accommodations you would like to make to preserve your personal space and routines?

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Which strategies have you found effective in maintaining a balance between medical needs and personal comfort?

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How can we adapt your living environment to better accommodate your medical needs while preserving familiarity and comfort?

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Are there any resources or support services you would like to explore to help maintain your personal space and routines?

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What role do you envision your primary/supporting care partners fulfilling to support you in preserving your space and routines?

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How do you envision striking a balance between medical necessities and maintaining a sense of familiarity and comfort in your living space?

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## Addressing Spiritual Needs

My place of worship is: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

Telephone number: \_\_\_\_\_

Worship leader: \_\_\_\_\_

Times/Days of worship: \_\_\_\_\_

Does your place of worship offer online viewing/participation?: Yes \_\_\_ No \_\_\_

Does your place of worship offer in-person visitations?: Yes \_\_\_ No \_\_\_

What role does spirituality play in your life, and how does it contribute to your overall well-being?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

In which worship groups or service organizations do you participate?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

If you don't participate in a worship group or service organization, which would you like to try?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Are there any medical barriers to your active participation in worship-related activities? If so, how can we work to overcome them?

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How do you envision incorporating spirituality into your life-care plan?

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Which specific spiritual practices or rituals are most important to you?

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How do you feel your spiritual needs can be best supported by your care partner(s) and/or care team?

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Which additional support or resources do you feel would enhance your spiritual well-being?

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## Empowering Advocacy

Are you currently (or are you interested) in participating in clinical trials or research studies related to your diagnosis? If so, which one(s) would best fit your needs?

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Have you considered sharing your personal journey with others to provide support and encouragement? If so, which activities would you be most comfortable with?

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Have you considered advocating for awareness and education about living well with your diagnosis in your community? If so, which activities would you be most comfortable with?

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Are there any specific topics or aspects of living well with your diagnosis that you are passionate about educating others on?

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Which specific networks or resources would you like to connect with to further your advocacy efforts?

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Are there any challenges or barriers you anticipate encountering in advocating for a life worth living?

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What support or assistance do you need to effectively advocate for yourself and others?

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How do you envision your advocacy efforts contributing to your overall quality of life and sense of purpose?

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## Planning for the Future

What are your current financial goals and priorities for the future?

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Have you considered the importance of Medicaid planning in your long-term care strategy? If so, how do you envision asset protection playing a role in your future financial planning?

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Have you consulted with a financial advisor or elder law attorney to discuss Medicaid and VA planning options? If not, do you have a preferred advisor or attorney with whom you would like to be connected?

Yes \_\_\_ No \_\_\_

Preferred advisor/attorney: \_\_\_\_\_

Phone number: \_\_\_\_\_

Address: \_\_\_\_\_

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Do you have a comprehensive estate plan in place that addresses your long-term care needs and preferences?

Yes \_\_\_ No \_\_\_

Are you aware of the eligibility criteria and requirements for VA aid and attendance benefits? If not, which areas do you have questions about?

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Are you familiar with the potential benefits and limitations of Medicaid and VA aid and attendance benefits? If not, in which areas would you like more education/resources?

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What steps have you taken so far/previously to safeguard your assets and ensure financial security as you age?

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How do you plan to balance your current financial obligations with the need to plan for future care costs?

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Have you explored alternative funding options or resources to supplement your long-term care planning efforts?

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Do you have any barriers to actively participating in your financial/legal/estate planning process? If so, how may your care partner(s) help or provide additional resources?

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# **STEP THREE**

**Taking Care of Those  
Who Take Care of Us**

## Step 3: Taking Care of Those Who Take Care of Us

This step of the life-care planning process requires acknowledgment of the unsung heroes: the primary care partners. Recognize the vital roles they play, whether they're a live-in caregiver or someone who frequently drives to doctor appointments, cooks meals and performs household duties.

Those who give care also need care for devoting time and effort (and sometimes even experiencing physical and emotional stress) Because they're often the glue holding everything together, let's plan to ensure all care partners receive the support, time off and appreciation they deserve.

- **Honoring the Backbone:** Acknowledge the significance of care partners and the weight they carry. (Page 40)
- **Support, Time Off & Resources:** We provide a wealth of resources designed to assist caregivers in receiving the support they require, ensuring they get the time off they deserve, and acknowledging their efforts with genuine appreciation. (Page 43)
- **Maureen's Personal Insight:** I understand the challenges and emotions from my personal experience as the primary care partner for my husband, Brian. (Page 45)
- **Avoiding Frustration & Overwhelm:** Care partners often find themselves overwhelmed, frustrated and, at times, forgotten. We bring awareness to available help and solutions. (Page 62)
- **Empowering the Care Partner Team:** By providing support opportunities and resources, we aim to make sustainable caregiving feasible across the entire continuum of care. (Page 49)

By addressing caregiver needs, we strengthen the foundation of care and foster an environment where both the care partner and the care recipient thrive together.

The next few pages provide space to answer questions and provide relevant information.

## Honoring the Backbone

In the journey of caregiving, it's crucial to recognize the unsung heroes who serve as the backbone of our support system: the primary care partners. Whether they're a spouse, a family member or a close friend, these individuals play a pivotal role in ensuring the well-being of their loved ones. From providing hands-on care to managing household duties and coordinating medical appointments, primary care partners devote their time, energy and resources to meet the needs of those they care for.

Given the demands of care partnering, it's essential to pause and acknowledge the significance of their contributions and the immense weight they carry on their shoulders.

The “Honoring the Backbone” section of our life-care planning process is dedicated to recognizing the vital role played by primary care partners and addressing their needs for support, time off and resources. By shining a spotlight on their tireless efforts, we aim to foster a culture of appreciation and gratitude for the dedication and sacrifices made by care partners. Through open communication and collaboration, we can ensure that the care partner team works cohesively to meet the needs of both the individual receiving care and the care partners themselves.

To navigate this section effectively, let's reflect on some key questions that prompt us to consider how we currently (or intend to) support and appreciate our primary care partners, as well as how we can better meet their needs. By exploring available resources and support services, implementing strategies for self-care, and fostering open communication within the care partner team, we can create a supportive environment where care partners feel valued, supported, and empowered at each stage of the journey – in good health or bad. Together, let's honor the backbone of our care partner team and ensure that their well-being remains a top priority as we navigate the challenges of caregiving with compassion and resilience.

How do you currently recognize and appreciate the vital role played by your primary care partner(s) in your life?

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How can you express genuine appreciation for the dedication and sacrifices made by your care partner(s)?

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What specific challenges or stressors do your care partner(s) face in their caregiving role, and how can you as a care recipient help alleviate these challenges?

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Have you explored available resources and support services that could benefit your care partner(s) in their caregiving journey?

Yes \_\_\_ No \_\_\_

If not, which resources or care professionals would help you better understand the services available in your care community?

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How can you as a care recipient foster open communication and collaboration within your care partner team to ensure everyone's needs are met?

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## Support, Time Off & Resources

The crux of this section, quite clearly, is to consider the responsibilities and feelings of the caregiver. Indeed, it's one of the most stressful jobs in the world – and it often doesn't pay one cent for the trouble. There are now more than 53 million unpaid adult caregivers in the U.S., and the vast majority of those continue to work at least one full-time job in addition to being a primary care partner. Millions of others also care for their children simultaneously.

When it comes to elder care, the focus often lands on the recipient of care. Despite best efforts, it's all too easy to overlook the tireless warriors standing steadfastly by their loved one(s). Care partners need support. They need time off. They need respite care and other resources. They are the unsung heroes who navigate the challenges, bear the emotional weight, and selflessly dedicate themselves to the well-being of others.

This “Support, Time Off & Resources” section ensures our care partners receive the support needed to navigate the complexities of caregiving. Caregiver Support and Resources, LLC has curated a wealth of resources specifically designed to assist caregivers in their journey, from practical support services to opportunities for respite care and self-care activities. By providing access to these resources, we aim to alleviate the challenges on care partners, empower them to seek the help they need, and ultimately enhance their overall well-being.

But we must first seek to understand. As care partners embark on this crucial phase of the life-care planning process, it's essential to pause and reflect on the resources required to be an effective caregiver. Through the following series of thought-provoking questions, we encourage care partners and care recipients alike to explore their needs, preferences and challenges. By engaging in this introspective process, individuals can gain clarity on the support and assistance they require, paving the way for a more informed and holistic approach to care partnering.

Are you aware of the importance of self-care for care partners and the potential consequences of neglecting their own well-being?

Yes \_\_\_ No \_\_\_

If not, which resources or care professionals would help you better understand the physical and emotional toll of caregiving?

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Have you discussed with your care partner(s) their needs for support, time off, and resources to help them cope with the demands of caregiving?

Yes \_\_\_ No \_\_\_

If not, how do you plan to ensure that your care partner(s) receive the time off they need to rest and recharge?

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How do you express gratitude and appreciation for the hard work and dedication of your caregiver(s)? Have you asked them what would make them feel appreciated? List some of those things below.

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Describe your plan for your caregiver to have time off to rest and recuperate

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## Maureen's Personal Insights

From a personal standpoint, navigating the care partner journey has been both challenging and rewarding. For many years, I've served as the primary care partner for my life partner, Brian, who lives with Alzheimer's disease and vascular dementia. Through both personal and professional experiences, I've gained invaluable insights into the emotional and practical aspects of caregiving, which I'm passionate about sharing with others facing similar challenges. I invite you to explore my regularly updated blog at [www.caregiversupportandresources.com/news](http://www.caregiversupportandresources.com/news), where I offer candid stories, professional advice and compassionate guidance to empower fellow care partners and elders on their journey. Whether you're seeking tips on managing care partner stress, understanding medical conditions or simply seeking encouragement, my blog supports you every step of the way.

I also invite you to check out our social media accounts, where we frequently share my own and third-party articles and insights about realities facing elders and their care partners.

As someone who understands the joys and struggles of caregiving firsthand, I'm dedicated to offering a beacon of hope and understanding to caregivers worldwide. My experiences caring for Brian personally and thousands of others as a professional life-care planner and Board-certified Patient Advocate in Florida have given me unique perspectives and invaluable wisdom. My online resources are safe and supportive spaces for caregivers and individuals to find the resources and solidarity they need.



## Avoiding Frustration & Overwhelm

Every caregiver has experienced frustration and overwhelm. If they say they haven't, they're lying. These strong feelings often lurk just beneath the surface, threatening to engulf care partners in a tidal wave of emotions. Recognizing the gravity of these challenges, we invite care partners to take a step back for self-reflection and introspection. In this "Avoiding Frustration & Overwhelm" section, we provide a brief series of thought-provoking questions tailored specifically to care partner experiences, to articulate their perspectives, feelings and experiences openly and honestly.

These questions provide a safe space to voice their frustrations, fears and concerns without judgment or reservation. From the relentless demands of caregiving to the emotional rollercoaster of navigating evolving circumstances, each question encourages care partners to delve into the heart of their experiences, unearthing hidden truths and unspoken challenges.

Through this process of self-exploration, care partners can gain clarity on their needs, identify areas of support, and develop coping strategies to navigate the turbulent waters of caregiving with resilience and grace.

The following questions are for care partners to answer for themselves. By providing their own perspectives, feelings and experiences, we can develop a more comprehensive understanding of everyone's needs on the caregiving journey:

Are you feeling overwhelmed, frustrated and/or burned out by the demands of caregiving?

Yes \_\_\_ No \_\_\_

If so, which strategies can you use to lessen the challenge, if only for a moment? Which resources or professional services would you like to be connected to?

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Are you aware of the assistance and solutions that could alleviate some of your caregiving challenges? Or have you encountered challenges in accessing available support and resources?

Yes \_\_\_ No \_\_\_

If so, how can you overcome those challenges or barriers to accessing those resources?

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Do you feel like your needs as a care partner are sometimes overlooked or forgotten?

Yes \_\_\_ No \_\_\_

If so, what strategies or resources could you implement to advocate for your personal needs?

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Are you open to discovering new approaches and resources that could ease the challenges of caregiving?

Yes \_\_\_ No \_\_\_

If so, which approaches and resources would best benefit your personal lifestyle and style of caregiving?

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How can we assist you in avoiding frustration and overwhelm in your caregiving role?

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## Empowering the Care Partner Team

It's crucial to recognize that no care partner should carry the caregiving weight alone. Building a team mentality not only lightens the load but also fosters a sense of unity and support among care partners. By leaning on each other and pooling our strengths, we create a robust network capable of addressing the multifaceted needs of our loved ones. Whether it's family members, friends, or healthcare professionals, each member of the care partner team plays a vital role in providing comprehensive care and ensuring the well-being of the individual receiving care.

Moreover, embracing a team approach ensures that no aspect of care falls through the cracks. By tapping into the expertise of various professionals in the continuum of care, we gain access to specialized knowledge and resources tailored to specific needs. From medical specialists to financial advisors and legal experts, each professional brings unique insights that contribute to a holistic care plan. By working collaboratively with these professionals, we can navigate the complexities of caregiving more effectively and make informed decisions that prioritize the best interests of our loved ones.

Above all, fostering a team mentality cultivates a culture of support and camaraderie, where care partners can find solace and encouragement amidst the challenges of caregiving. Knowing that we're not alone in our journey can provide much-needed reassurance and alleviate feelings of isolation. By coming together as a team, we create a community of caregivers dedicated to supporting each other through the highs and lows of caregiving, ensuring that no one bears the burden alone.



# **STEP FOUR**

**Final Stages Planning**

## Step 4: Final Stages Planning

Death is one of life's only certainties. (What's that saying about death and taxes?) Here we focus on comfort care, final arrangement planning, end-of-life planning and preparing to say goodbye. Recognizing that each person's journey is unique, here are some possible ideas, resources and tasks for this step:

- **Senior Living and Long Term Care Questionnaire:** This section is designed for you to go through these questions as you prepare for a senior living or long term care facility (Page 52)
- **Living Life to the Fullest:** Preparation is key to empowering each person to live their life to the fullest in every stage – even in dying moments. Plans may include the presence of certain people, ensuring comforting (Page 54)
- **End of Life Planning:** Making sure to identify what needs you have for the end of life, and that your wishes are communicated clearly to your care partners. (Page 57)
- **Celebrating Your Life:** This section allows you to identify what your celebration of life should look like. (Page 58)
- **Final Arrangements:** There are a number of details your family and care partners will need when it comes to your final arrangements. This worksheet gathers that information in one place. (Page 60)

This step is a holistic approach to the final stages, ensuring that individuals and their care partners face this phase with dignity, preparedness, and a sense of value in the journey they've undertaken together.

The next few pages provide space to answer questions and provide relevant information.

## SENIOR LIVING AND LONG-TERM CARE COMMUNITY QUESTIONNAIRE:

*Ask to tour common areas and see an apartment. Communities will be able to do live virtual tours to give you a real-time look in also.*

- What's the communication protocol during an emergency?
- What is their protocol to communicate with family/Caregiver during an emergency such as if your loved one must go to the hospital, during a hurricane, etc.?
- Resident to Caregiver ratio: This will give you an idea of how much one-on-one care they will get.
- Current visitation policies and procedures? COVID policies and procedures: How are they protecting their residents and staff?
- Dining: Is there all-day dining or set mealtimes?
- Ask to look at a menu. Is there in-room dining available? Do they accommodate special diets (gluten free, vegetarian, etc.)
- Activities: What activities do they offer to residents?
- Ask to see a calendar. What are current protocols for residents to do activities or trips out of the community?
- Do they have an in-house physician?
- Do they offer in-house physical and/or occupational therapy?
- Are there transportation services?
- What is the current move-in process/protocol?
- Do they offer Hospice or end of life care?

- Understand apartment sizes and costs. What services are included? Ask for a price sheet and room dimensions, as well as list of services/amenities included in base cost.
- What are the care levels? What do they include & cost?
- Is care a la carte or all inclusive?
- What license(s) do they hold? The three licenses are Standard, LNS and ECC. All allow different levels of care. It's important the community's license is appropriate for the care your loved one requires.
- Are Caregivers and staff trained to care for your loved one's specific needs? This is especially important for Dementia, Parkinson's Disease and other higher needs residents.
- Does the community administer medications? Any restrictions? Especially important if a resident is prescribed certain psychiatric drugs, insulin, etc. Speak to Director of Nursing. The Director of Nursing will be responsible for creating and managing your loved one's care plan, so make sure you speak to him/her and feel confident about the discussion. Speak to Executive Director. The Executive Director 'oversees the entire staff at the community. Their management and communication style usually "trickles down", so speaking to him/her is important.
- Is there a nurse onsite 24/7, or just on-call? Who is your point of contact when you have questions or concerns?
- Is there a one-time community fee?

## Living Life to the Fullest

As we prepare for the end of our lives, it's important to think about how we want to spend our final moments and be remembered by loved ones. This worksheet helps you consider who and what you'd like present during your end-of-life celebration. From friends and family to music and spiritual rituals, these questions guide you in creating a personalized plan that reflects your values and desires, empowering you to shape a meaningful experience for yourself and your loved ones.

Who would you like to have present during your final moments? Consider family members, close friends, spiritual advisors, healthcare providers, or other significant individuals.

Name \_\_\_\_\_ Relationship \_\_\_\_\_

Telephone Number: \_\_\_\_\_

Name \_\_\_\_\_ Relationship \_\_\_\_\_

Telephone Number: \_\_\_\_\_

Name \_\_\_\_\_ Relationship \_\_\_\_\_

Telephone Number: \_\_\_\_\_

Name \_\_\_\_\_ Relationship \_\_\_\_\_

Telephone Number: \_\_\_\_\_

Name \_\_\_\_\_ Relationship \_\_\_\_\_

Telephone Number: \_\_\_\_\_

Name \_\_\_\_\_ Relationship \_\_\_\_\_

Telephone Number: \_\_\_\_\_

Are there specific friends or family members you would like to invite to say goodbye?

Name \_\_\_\_\_ Relationship \_\_\_\_\_

Telephone Number: \_\_\_\_\_

Name \_\_\_\_\_ Relationship \_\_\_\_\_

Telephone Number: \_\_\_\_\_

Name \_\_\_\_\_ Relationship \_\_\_\_\_

Telephone Number: \_\_\_\_\_

Are there specific songs or genres of music that hold special meaning to you and that you would like to have played during your time with loved ones?

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Would you like to incorporate any religious or spiritual rituals during your final moments?

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Think about whether you would like to have certain items or surroundings that bring you comfort, such as favorite blankets, photographs, or scents.

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Consider whether there are any special requests or guidelines you would like to communicate to your family and friends to ensure that your wishes are honored.

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## End of Life Planning

Making plans for the last moments of your life.

Do you have a DNR order? Yes \_\_\_ No \_\_\_

If not, in which condition would you prefer to be resuscitated?

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At end-of-life, do you have preferences to receive or not receive certain pain medications?

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Do you have any religious/cultural stipulations that prohibit certain treatments or medications at end of life?

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## Celebrating Your Life

Making plans for your family to celebrate your life after you are gone.

Do you have any specific wishes for how your life should be celebrated after you pass away?

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Think about whether you would like to have a traditional funeral service, a celebration of life ceremony, or another type of gathering to honor your memory.

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Are there any particular readings, poems, or quotes that resonate with you and that you would like to be shared during your end-of-life celebration?

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Consider whether there are any meaningful passages or words of wisdom that you would like to be included in the ceremony.

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Are there any specific wishes or instructions you have for your loved ones regarding your end-of-life celebration?

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# FINAL ARRANGEMENTS

Making funeral arrangements at the time of loss is extremely difficult for those left behind. You can rest easy knowing that everything will be taken care of according to your wishes when you make pre-arrangements, eliminating added stress on your loved ones both emotionally, and

My Final Arrangements are made with::

Name: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Telephone: \_\_\_\_\_

Email: \_\_\_\_\_

My Paperwork/Contract is Kept: \_\_\_\_\_

\_\_\_\_\_

Notes:

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## Conclusion

Alas, we've come to the end of "Because I Love You: My Book About Me." If you're just completing this book of insights and exercises, you and your loved one are likely just beginning **your life-care planning journey for a life worth living with dementia**. As I know from both personal and professional experience, that journey is long and arduous. Even to the most devoted, compassionate and capable care partners, the answers are rarely obvious. The decisions are never easy.

And that's OK. Because our goal here is to be prepared. Preparation is the ultimate act of love for your loved one living with dementia – and the rest of the care-partner team.

This simple book of insights, caregiver documents and insightful self-reflection encapsulates the essence of caregiving: the love, the challenges and the transformative power of compassion. I hope you've already begun to gain valuable insights into the intricacies of living well with and navigating the complexities of Alzheimer's and other types of dementia. From the importance of person-centered care to the significance of honoring individual preferences, this book can be adjusted as life evolves and consulted repeatedly as a roadmap for care recipients and care partners seeking guidance and support.

The pages of "Because I Love You: My Book About Me" are a testament to preparation in honoring the human spirit and the unwavering power of love in the face of adversity. By embracing compassion and understanding, we can forge a path forward that honors the dignity and autonomy of care.

As we reach the end of this transformative journey, I invite you to continue exploring the depths of caregiving with me. Follow us on social media and check out our regularly updated blog at [www.caregiversupportandresources.com/news](http://www.caregiversupportandresources.com/news). Whether you're seeking personalized guidance, resources or simply a listening ear, I'm here to support every step. Reach out to me at [maureen@caregiversupportandresources.com](mailto:maureen@caregiversupportandresources.com) or (727) 409-2292, and together, let us navigate the challenges, celebrate the triumphs and create a compassionate and fulfilling caregiving experience for you and your loved ones.

Thank you for allowing me to be a part of your journey.

Your friend,

*Maureen Rulison*



**Maureen Rulison, BCPA, CMP**  
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## **ABOUT THE AUTHOR**

**Maureen Rulison, BCPA, CMP, is the President and Founder of Caregiver Support and Resources, LLC, located in Clearwater, Florida. With a career spanning nearly three decades in life-care planning and patient advocacy, Maureen brings a wealth of expertise and personal insight to her work.**

**Having served as a care partner herself, Maureen intimately understands on a personal level the daily challenges faced by elders and their care partners. Her journey alongside her life partner, Brian LeBlanc, who lives with Alzheimer's disease and vascular dementia, fuels her passion for supporting individuals and families in crafting comprehensive life-care plans for a life worth living.**

**In addition to her professional qualifications as a Board-certified Patient Advocate in the state of Florida, Maureen's personal experiences inform her approach to all facets of caregiving. Through her dedication and commitment, Maureen strives to empower individuals and families to navigate the complexities of aging, illness, and end-of-life planning with compassion and dignity.**

## **ABOUT THIS BOOK**

**"Because I Love You: My Book About Me" is a comprehensive guide to creating a life worth living through pre-planning and team building. Rooted in Maureen Rulison's extensive experience and personal journey, this book offers a roadmap for individuals and families to build or improve their life-care plans.**

**Divided into four essential steps, the book guides readers through the process of understanding personal preferences, fostering supportive care partner teams and addressing practical considerations for end-of-life planning. From gathering essential information to preserving joy and addressing spiritual needs, each step is designed to empower individuals to live their best lives, dealing with current care realities and preparing for the future.**

**Drawing from Maureen's vast network of professionals and resources, "Because I Love You" provides practical tools and insights to navigate the journey of caregiving with grace and purpose. Whether you're a care partner or individual planning for your own future, this book offers guidance, support and a compassionate approach to building a plan for a life worth living.**

