



# *Caregiver's Journal*

TO ACCOMPANY

LOVE, DIGNITY  
& PARKINSON'S

BY

TERRI PEASE, PH.D.

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# CAREGIVER'S JOURNAL

TO ACCOMPANY

LOVE, DIGNITY  
& PARKINSON'S

CREATED BY

*Terri Pease, Ph.D.*



# CONTENTS

## WELCOME LETTER

- Journal Instructions
- Prepare Your Mind and Spirit

## CHECK-INS AND REFLECTIONS

- **CHAPTER 1** - Not Just the Muscles
- **CHAPTER 2** - Resources for the Journey Ahead
- **CHAPTER 3** - Parkinson's, the Thief.
- **CHAPTER 4** - Dignity and Love.
- **CHAPTER 5** - Caregiver Capacities/What You Can Do.
- **CHAPTER 6** - Planning Your PD Future.
- **CHAPTER 7** - Adjusting Your Relationship
- **CHAPTER 8** - Endings and Beginnings.

## FINAL REFLECTION

## FURTHER RESOURCES

## MEET TERRI PEASE





# *PART ONE*



## PREPARE YOUR MIND AND SPIRIT

My happiness grows in direct proportion to my acceptance, and in inverse proportion to my expectations.

MICHAEL J. FOX  
*diagnosed with PD in 1991*



## *Welcome caregiver!*

I'm glad that you've chosen to read *Love, Dignity and Parkinson's*. It means so much to me to be allowed to share my experience of PD caregiving with you.

I hope that reading my book, and journaling here, will help you to design a path for yourself and your PWP that is easier and more gratifying for both of you.

*Terri*

# *How to use this journal*

Please do notice that Love, Dignity, & Parkinson's is not just a book of tips for caregiving. Instead it helps you with the mindset to maintain yourself and your partner in your Parkinson's Life.

**The Journal has two parts**

**Part One** helps you settle your mind and spirit for the things you will learn as you read through the book

**Part Two** Gives you a section for each of the eight chapters of Love, Dignity,& Parkinson's.

- First, you'll see the same Check-in that ends each chapter of the book, with room for you to write your responses.
- Then, you'll find space to reflect and record the thoughts that arise as you are reading, and to write down any quotes from the book that most speak to you.





# *If you can, dig a little deeper*

You might feel ready to look more closely at your current thoughts about caregiving. What questions, worries, and obstacles are on your mind? What problems will you need to solve?

Often we caregivers engage in a frenzied search for the one right thing that will restore our lives to their pre-Parkinson's state. If that cannot happen for you, what else would you like? How else would peace look for you and your PWP?

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# FIND PEACE- YOUR WAY



Health does not always come from medicine. Most of the time it comes from peace of mind, peace in the heart, peace in the soul. It comes from laughter and love.

---SOURCE. UNKNOWN

*I believe that it is possible to find peace as a caregiver.*

*What does peace look like to you? How will you recognize peace when you find it?*



# *PART TWO*



## JOURNAL AS YOU READ

Life is a series of natural and spontaneous changes. Don't resist them - that only creates sorrow. Let reality be reality. Let things flow naturally forward in whatever way they like.

LAO TZU



## Check-Ins for Chapter One

# NOT JUST THE MUSCLES

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Think of this first check-in as a kind of status report. Read each item in the chart. Ask yourself, “How are you doing? Where are things today?” Briefly describe the changes you have noticed since PD entered your lives. At the end of each section, use the blank lines to add in other items in that category that are specific to your situation.

Don’t let this process overwhelm you. Just make quick notes to yourself, making sure that you focus first on yourself. Then turn your attention to your Partner with Parkinson’s. How is he or she doing?

Working in this order may be unfamiliar and even uncomfortable. After all, most of us feel that once our partner is being affected by PD, our first responsibility is to them rather than ourselves.

I’m sure that you won’t lose track of the chance to think about your partner, so I want to be sure that you think about you. Start there because noticing how things are with you helps to make sure that your PWP has a well-functioning caregiver. But these questions are also important because you are a whole person and are entitled to pay attention to your own wants and needs.

# Check-ins for Chapter One

## Relationships

*Briefly describe the status of each relationship. Has PD changed them?*

- |   |   |
|---|---|
| <input type="checkbox"/> PWP                          | <input type="checkbox"/> Children/Grandchildren |
| <input type="checkbox"/> Parents                      | <input type="checkbox"/> Other family           |
| <input type="checkbox"/> Friends                      | <input type="checkbox"/> Community              |
| <input type="checkbox"/> Work/professional colleagues |   |

*Now for your PWP. Based on your own observations, how are these relationships for them?*

- |   |   |
|---|---|
| <input type="checkbox"/> PWP                          | <input type="checkbox"/> Children/Grandchildren |
| <input type="checkbox"/> Parents                      | <input type="checkbox"/> Other family           |
| <input type="checkbox"/> Friends                      | <input type="checkbox"/> Community              |
| <input type="checkbox"/> Work/professional colleagues |   |

## Practical Things

*How are these practical aspects of daily life today?*

- |   |  |
|---|--|
| <input type="checkbox"/> Daily cleaning and maintenance | <input type="checkbox"/> Income and money management                   |
| <input type="checkbox"/> House and yard maintenance     | <input type="checkbox"/> Adapting your home/safety and fall prevention |
| <input type="checkbox"/> Moving to a new home           | <input type="checkbox"/> Food shopping and meal preparation            |

*What do you notice about these practical things in your PWP's daily life?*

- |   |  |
|---|--|
| <input type="checkbox"/> Daily cleaning and maintenance | <input type="checkbox"/> Income and money management                   |
| <input type="checkbox"/> House and yard maintenance     | <input type="checkbox"/> Adapting your home/safety and fall prevention |
| <input type="checkbox"/> Moving to a new home           | <input type="checkbox"/> Food shopping and meal preparation            |

# Check-ins for Chapter One continued

## Life Course

*How is the course of your life?*

- |  |   |
|--|---|
| <input type="checkbox"/> Job and career path | <input type="checkbox"/> Education and Training |
| <input type="checkbox"/> Retirement          | <input type="checkbox"/> Economic well-being    |

*And now your PWP's life course. How are things?*

- |  |   |
|--|---|
| <input type="checkbox"/> Job and career path | <input type="checkbox"/> Education and Training |
| <input type="checkbox"/> Retirement          | <input type="checkbox"/> Economic well-being    |

## Self-care and Spirit

*How is your overall well-being?*

- |  |  |
|--|--|
| <input type="checkbox"/> Sobriety and recovery               | <input type="checkbox"/> Exercise and sports                     |
| <input type="checkbox"/> Vacation and travel                 | <input type="checkbox"/> Creative activities and hobbies         |
| <input type="checkbox"/> Religious observances & obligations | <input type="checkbox"/> Attendance at religious services/events |
| <input type="checkbox"/> Changed relationship with God       |  |

*And how is your PWP's overall well-being?*

- |  |  |
|--|--|
| <input type="checkbox"/> Sobriety and recovery               | <input type="checkbox"/> Exercise and sports                     |
| <input type="checkbox"/> Vacation and travel                 | <input type="checkbox"/> Creative activities and hobbies         |
| <input type="checkbox"/> Religious observances & obligations | <input type="checkbox"/> Attendance at religious services/events |
| <input type="checkbox"/> Changed relationship with God       |  |

# Check-ins for Chapter One continued

## Health

*How is your health?*

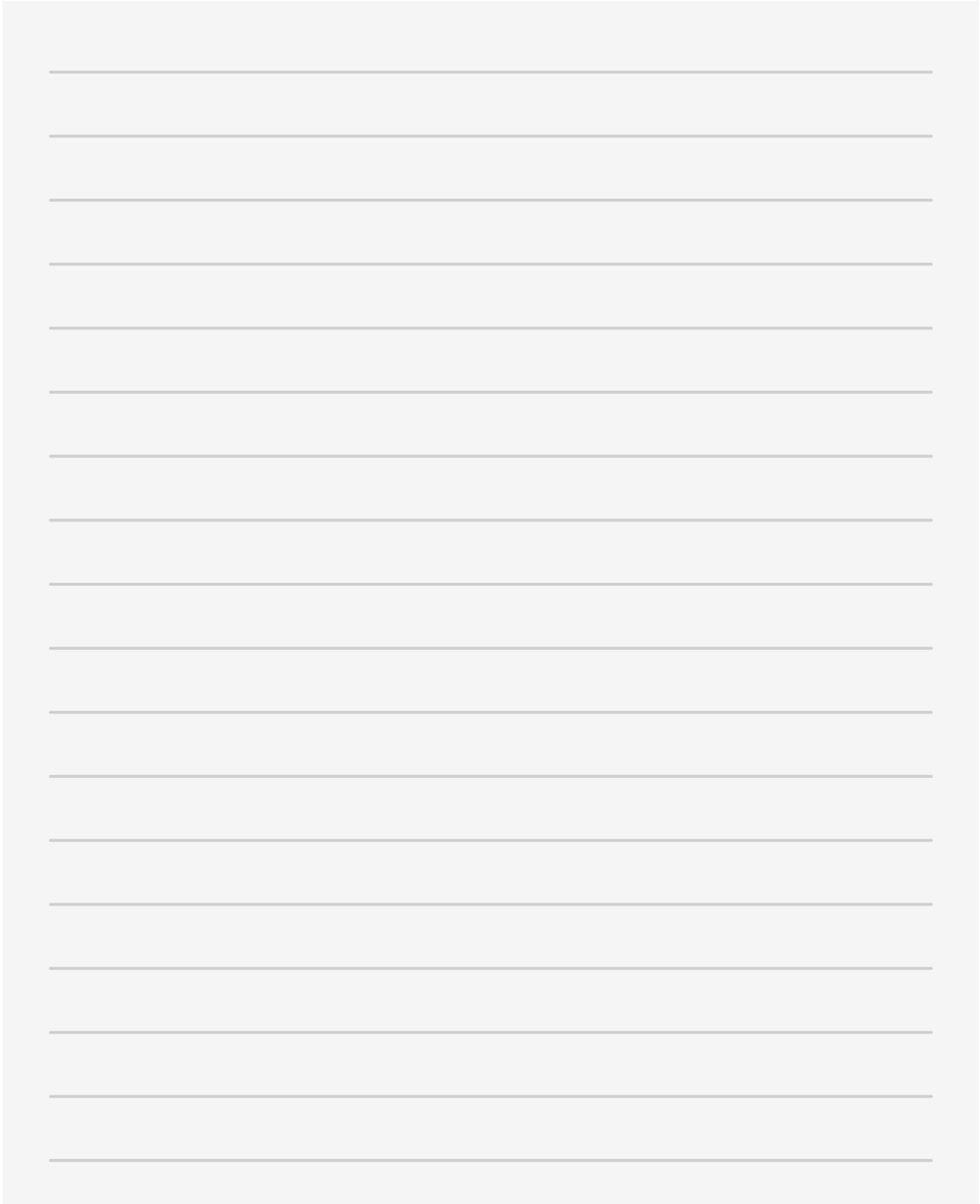
- |   |   |
|---|---|
| <input type="checkbox"/> Your own physical health               | <input type="checkbox"/> Your PWP's physical health |
| <input type="checkbox"/> Health of children, parents,<br>others | <input type="checkbox"/> Your own mental health     |
| <input type="checkbox"/> Your PWP's mental health               | <input type="checkbox"/> Mental health of others    |

*Apart from PD itself, how are your partner's mental and physical health?*

- Your PWP's physical health
- Your PWP's mental health

# *Reflections on Chapter One*

## NOT JUST THE MUSCLES

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Check-Ins for Chapter Two

## RESOURCES FOR THE JOURNEY AHEAD

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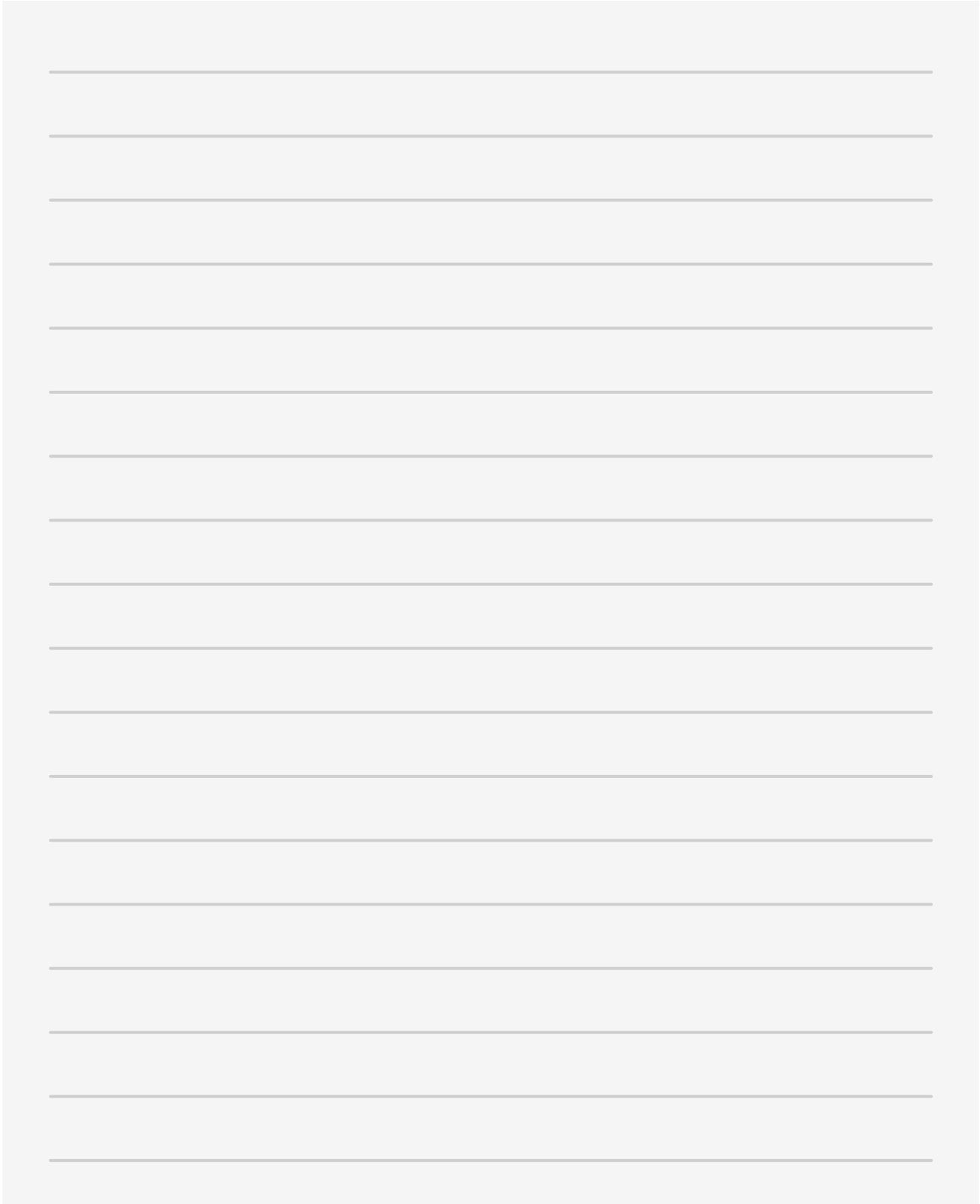
This chapter has set the stage for you to look at the initial resources that are necessary to virtually every PD caregiver. This check-in will give you a sense of where you might start to gather these essential assets as you move through life with Parkinson's.

# Check-ins for Chapter Two

- What preparations have you and your PWP made for changes to come?
- Are there other preparations you'd like to make? How can you start?
- How easy is it for you and your PWP to communicate?
- If it is not easy, will you be able to improve communication with your PWP? How will you start?
- How have you begun to build the resources to sustain you as a caregiver?
- Where are you making room in your current social networks for the ways PD may change you?
- What might you do now to make it easier to reach out to others for help as the need arises?
- How else can you pave the way for an easier time in the future?

# *Reflections on Chapter Two*

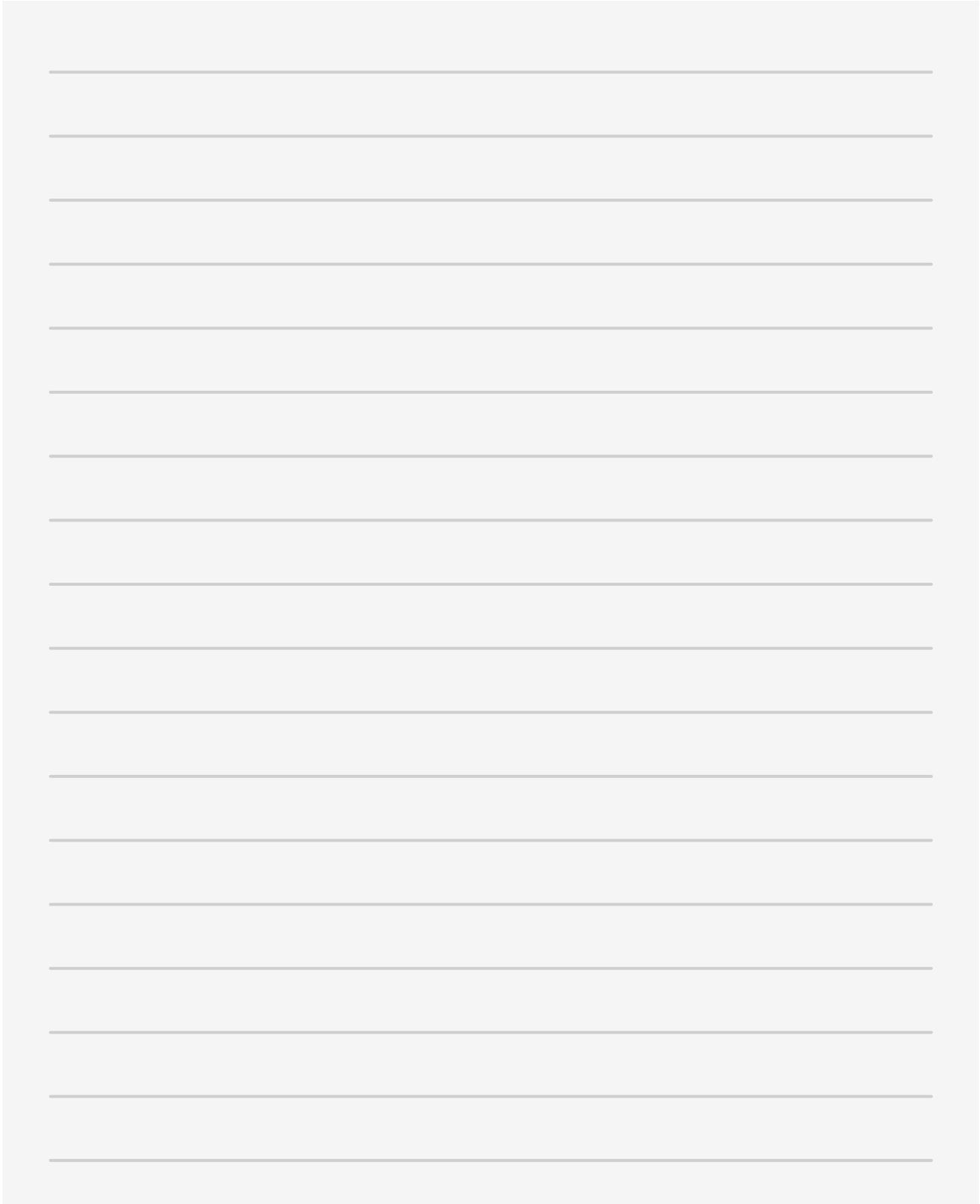
## RESOURCES FOR THE JOURNEY AHEAD



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# *Reflections on Chapter Two*

## RESOURCES FOR THE JOURNEY AHEAD

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Check-Ins for Chapter Three

## PARKINSON'S, THE THIEF

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This chapter has set the stage for you to look at the initial resources that are necessary to virtually every PD caregiver. This check-in will give you a sense of where you might start to gather these essential assets as you move through life with Parkinson's.

# Check-ins for Chapter Three

## Sleep

- How much this is affecting you
- How you have already adapted
- New adaptations you can make
- Help you can seek
- Other thoughts

## Thinking

- How much this is affecting you
- How you have already adapted
- New adaptations you can make
- Help you can seek
- Other thoughts

## Elimination

- How much this is affecting you
- How you have already adapted
- New adaptations you can make
- Help you can seek
- Other thoughts

# Check-ins for Chapter Three

## Affection

- How much this is affecting you
- How you have already adapted
- New adaptations you can make
- Help you can seek
- Other thoughts

## Learning

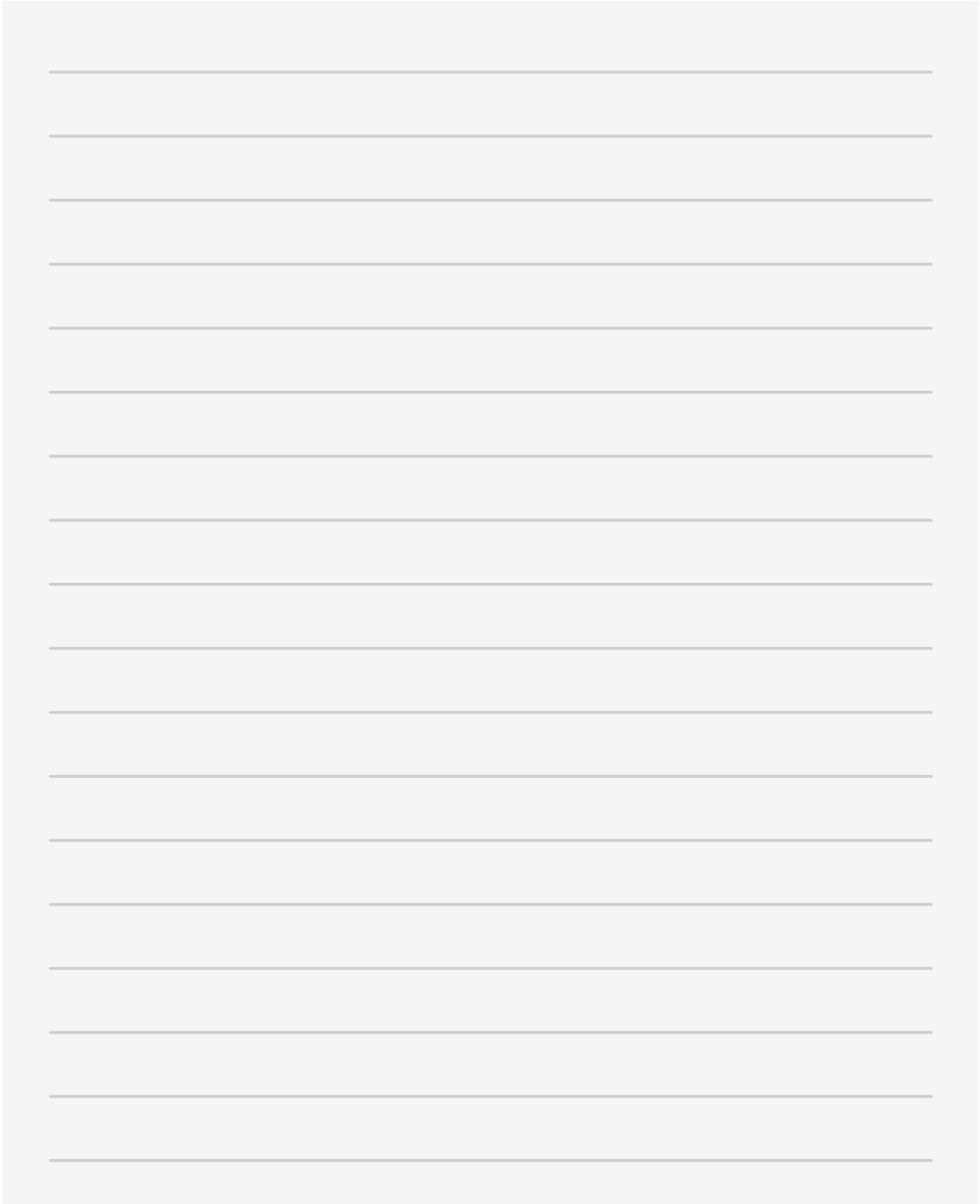
- How much this is affecting you
- How you have already adapted
- New adaptations you can make
- Help you can seek
- Other thoughts

## Sex and Other Impulses

- How much this is affecting you
- How you have already adapted
- New adaptations you can make
- Help you can seek
- Other thoughts

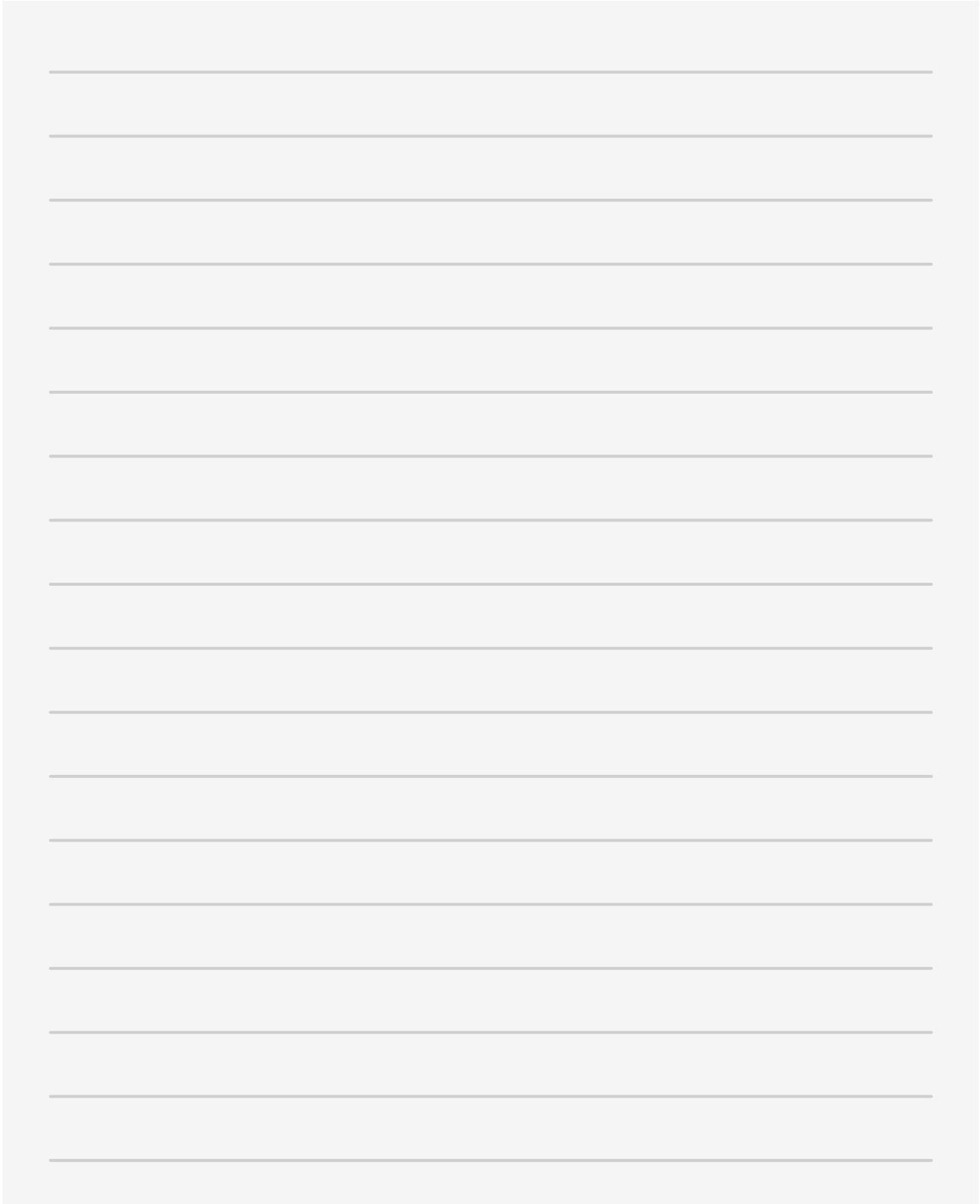
# *Reflections on Chapter Three*

## RESOURCES FOR THE JOURNEY AHEAD

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# *Reflections on Chapter Three*

## RESOURCES FOR THE JOURNEY AHEAD



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Check-Ins for Chapter Four

## DIGNITY AND LOVE

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No matter whether your relationship bank is full to overflowing, or seems mostly drained and nearly empty, there is love and respect to be found, even if you have to seek them out. It's especially important to remember that these essential elements for emotional well-being are due to each of you, not only to your PWP. Use this check-in to help improve the emotional stores you'll need.

# Check-ins for Chapter Four

## Your Emotional Bank Account

- What is the status of your invisible bank account?
- Can you draw on a strong balance, with mutual deposits of love, energy, and support from each of you?
- To add to your emotional bank, make sure that every day you say something loving to yourself. Start now and write down one loving statement from you, to you. It may seem insignificant to do this—but try it. It probably won't hurt.

## Expecting Change and Preparing for It

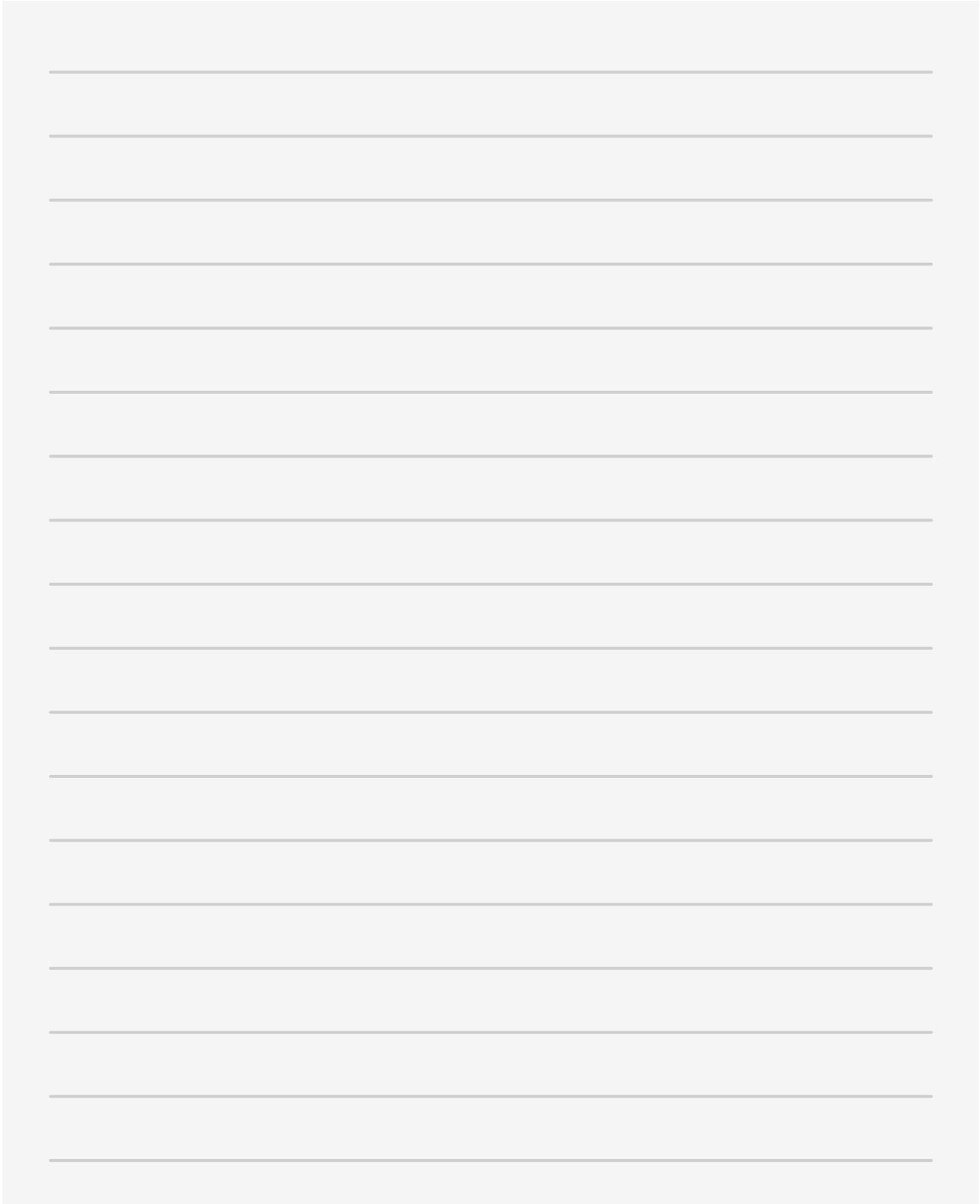
- Once you expect your relationship to change, you are prepared to respond to these changes in ways that will help maintain your own sense of dignity and your partner's, despite the extreme stresses of Parkinson's Disease.
- Which aspects of dignity are most important to you?
- How will you honor yourself for the ways in which you carry out the hard parts of caregiving?

## Write a Mantra for Yourself

- Many people use a repeated word or sentence, sometimes called a mantra, or mental tool, to strengthen their personal resolve, concentrate their minds, and to help reframe difficult situations.
- You can create your own mantra by writing out things about yourself and your life that you value. In the spirit of fake it 'til you make it your mantra can express something that you want to be true, even if it does not feel true today. Experiment with creating a mantra here.
- If this seems impossible, then start with this mantra, say it aloud, and then fix it up as you go along so that it reflects what you want for yourself: *I am doing a heroic job, under stressful and trying circumstances, and what I am doing matters!*

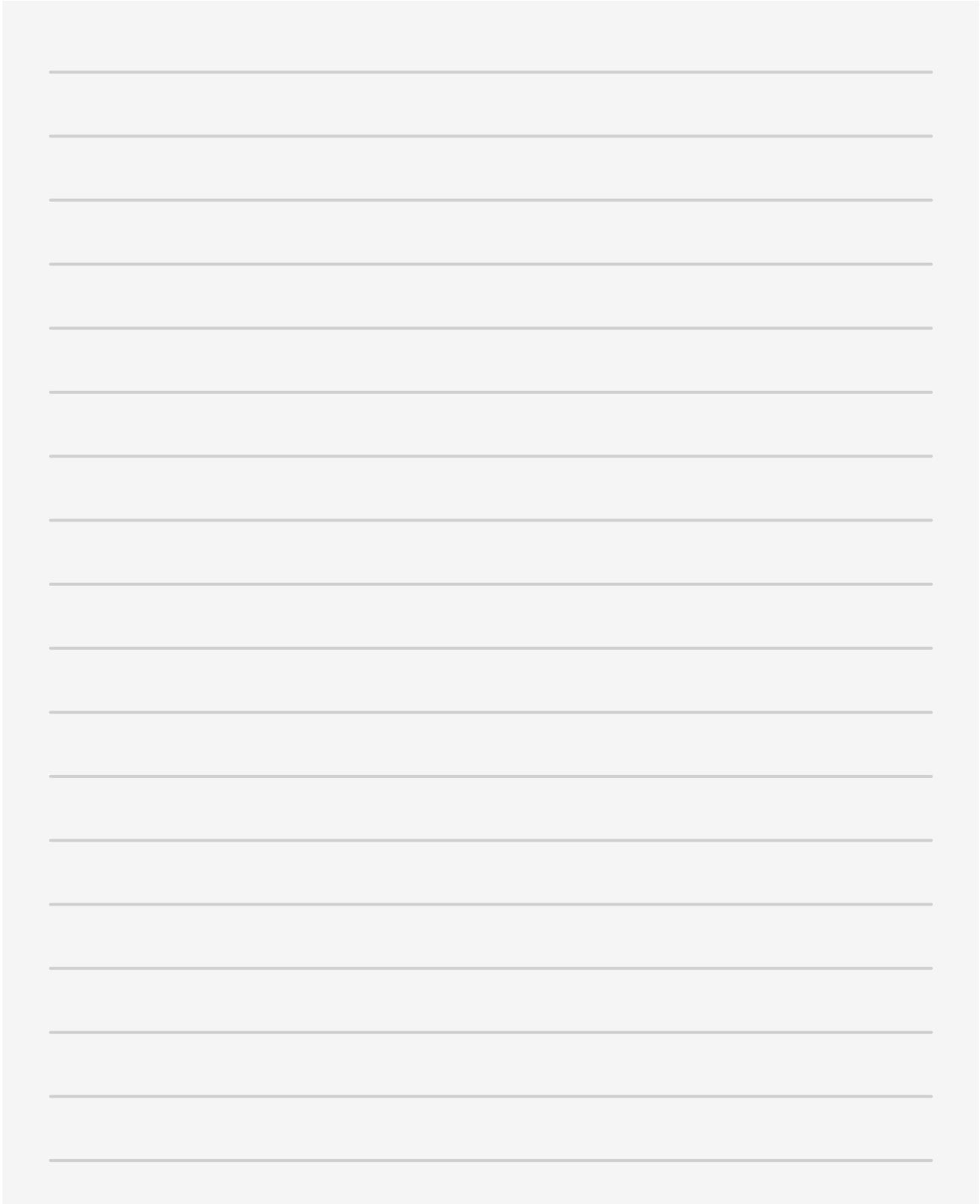
# *Reflections on Chapter Four*

## DIGNITY AND LOVE

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# *Reflections on Chapter Four*

## DIGNITY AND LOVE

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Check-Ins for Chapter Five

## CAREGIVER CAPACITIES OR WHAT YOU CAN DO

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Are you a natural caregiver? Some of us are. And others of us feel that we are pushing against our own inclinations in order to become the caregivers we want to be and that our PWP's deserve. And no one can perform every aspect of caregiving equally well. This check-in has three parts. Together, they will help you identify your sturdiest capacities and the ways in which your caregiving life will be strengthened by seeking other caregiving supports you will need.

# Check-ins for Chapter Five

## Part I—Are you a natural caregiver?

- Adaptability.** Are you a roll-with-the punches sort of person, or do you know that changes in your routine and habits make you uncomfortable?
- Tolerance for Isolation.** How important is it for you to have an active social life? Are you an introvert who is perfectly happy at home with a book or video and a favorite beverage? Will you find it hard to spend many days and evenings at home with your partner, without the social outlets you are used to?
- Generosity.** Some people are givers by nature. Caregiving becomes a natural extension of their usual way of interaction. Others are less patient with setting aside their needs to make someone else comfortable.
- Obligation.** Are you strongly motivated by a sense of duty or more of a maverick who wants to do her own thing?

## Part II—TLC for you

- A caregiver requires TLC, tender loving care.
- How much of the job of loving you has PD taken away from your PWP?
- How are you doing that job for them?
- Do you easily recognize when you are “out of gas” and need to stop and renew yourself? Or do wear yourself thin before your exhaustion makes you rest?
- Where else can you turn to receive the knowledge that you are loved and that your needs are important?

# Check-ins for Chapter Five

## Part III—Managing ADLs

Much of this book focuses on the non-motor aspects of Parkinson's. Still, the Activities of Daily Living are important too. Knowing what help you and your PWP need now and will need later can help you maintain wellbeing for each of you.

	ADLs you and your partner manage on your own	ADLs that you want help with now	ADLs that may require help in the future
Eating			
Bathing or showering			
Grooming			
Walking			
Dressing and undressing			
Transfers			
Toileting			

What steps will you take to find help with these ADLs?







Check-Ins for Chapter Six

## PLANNING YOUR PD FUTURE

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Have you been keeping a caregiving journal? If not, this is a good time to start one!

Having a private way to take note of your own real reactions, or an online community where you can speak your truth, can help you to step back and sort out what needs in your partnership are going unmet. The caregiving journal is also a good place to work on your personal plan for living a caregiving life.

# Check-ins for Chapter Six

- In your caregiving journal, record the warmest memories from your life before Parkinson's. Those good recollections can serve you as PD progresses.
- What are your thirsts? What is making you most tired and run-down?
- What are the deeply felt needs that must be met for you to feel whole?
- What steps have you taken to continue to identify the wellsprings that will supply your thirsts?
- Thinking about your warm memories, you own wellsprings and the ideas in Chapter Six. What might you do for your first Date With You?
- Once you decide on your Date, make a pledge to yourself. Writing down a plan helps solidify your intentions and will help you follow through for yourself and your own well-being and your PWP's as well.

*I promise, on behalf of \_\_\_\_\_,  
who is my Partner with Parkinson's, and myself, \_\_\_\_\_,  
that I will take myself on a date.*

*I will do this activity : \_\_\_\_\_*

*I have set \_\_\_\_\_ as the day and time that I will do this.*

*(signed) \_\_\_\_\_*







Check-Ins for Chapter Seven

# ADJUSTING YOUR RELATIONSHIP

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The shifting balance of energy, leadership, responsibility will happen. Instead of always needing to catch up as these changes occur, you can pay attention now to what you are discovering about the changing patterns in your relationship.

# Check-ins for Chapter Seven

- Take a moment to think about the balance of energy in your relationship. How might your PWP feel as his or her capacities start to falter?
- Many couples experience shifts in the balance of their relationship before the PD diagnosis occurs. Are there ways that this has happened to you? Does your new understanding of your partner's emotional changes make a difference in how you feel or clarify why things have changed?
- Many couples experience shifts in the balance of their relationship before the PD diagnosis occurs. Are there ways that this has happened to you? Does your new understanding of your partner's emotional changes make a difference in how you feel or clarify why things have changed?
- Have you taken on new roles or learned new skills to help keep life afloat in your household?
- What have you needed to let go of as PD progressed? How do you feel about that?
- How are you creating mementos of your own life? Are you taking photos, making videos, saving small souvenirs of your life? And if your answer is "I'm not," how will you change that?
- If you been expecting yourself to have no struggles and no sense of loss, what can you do about that? What is stopping you from offering this kind of empathy to yourself?
- Which ideas from Chapter Seven will help you take better care of your partner's caregiver—that is, to take good care of yourself?







Check-Ins for Chapter Eight

## ENDINGS AND BEGINNINGS

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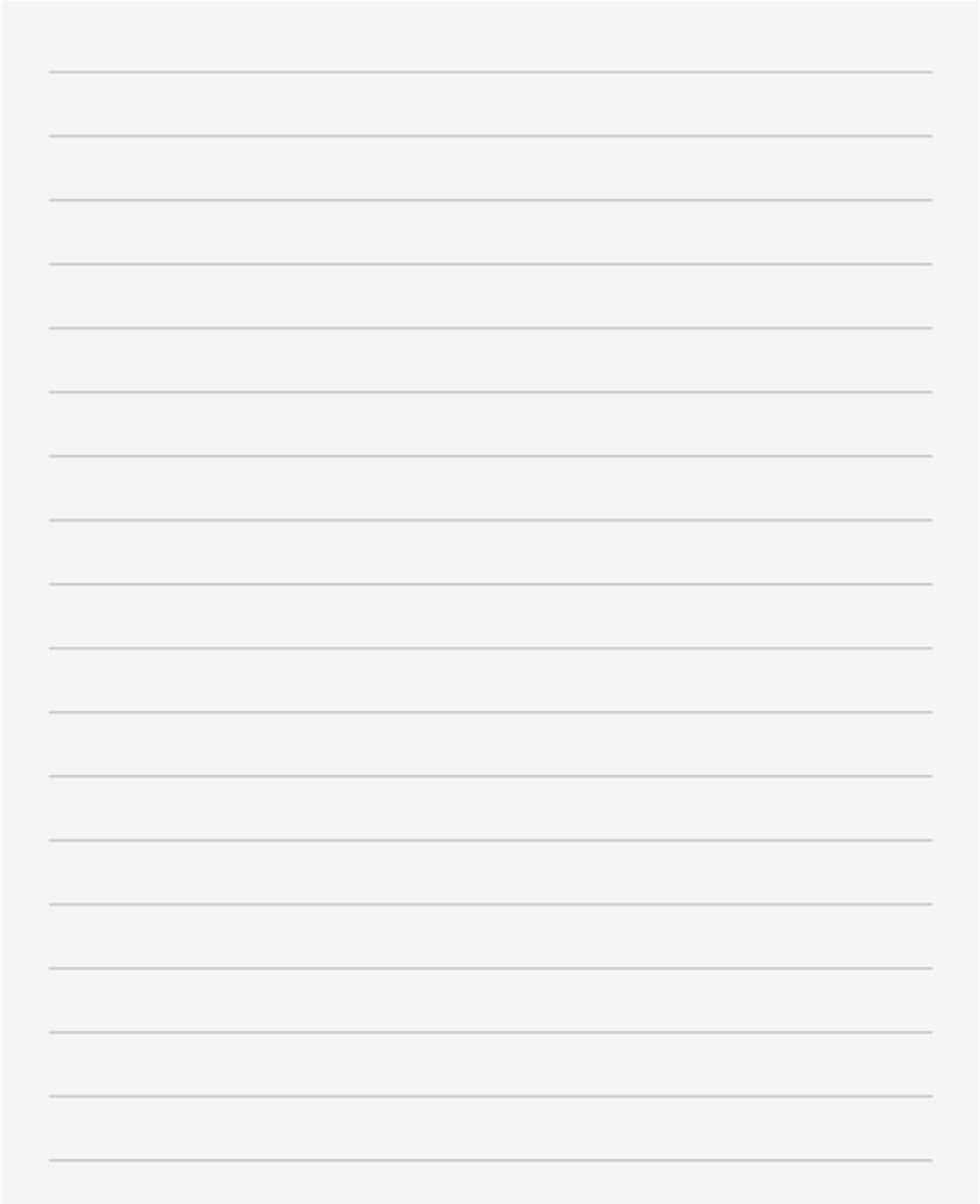
Neither you nor your PWP has chosen this path, and the overall truth of your individual PD caregiving story only emerges over time. Throughout this book I have wanted to help you recognize the choices that are in front of you, so that in choosing you escape feeling overwhelmed and diminished by the experience of caregiving. That way you will shape the way you carry out the role of caregiver, so that you approach this life with an open heart.

# *Check-ins for Chapter Eight*

- What are the choices you have made that allow you to continue to shoulder the responsibility of PD caregiving?
- Can you tell yourself why you are taking care of your Partner with Parkinson's?
- If you have decided to leave the relationship, can you give yourself permission to make good enough arrangements for your partner as you reset your own path? What are those arrangements?
- If you walk alongside your partner until his or her end, what end-of-life experts will you turn to for their expertise and companionship?

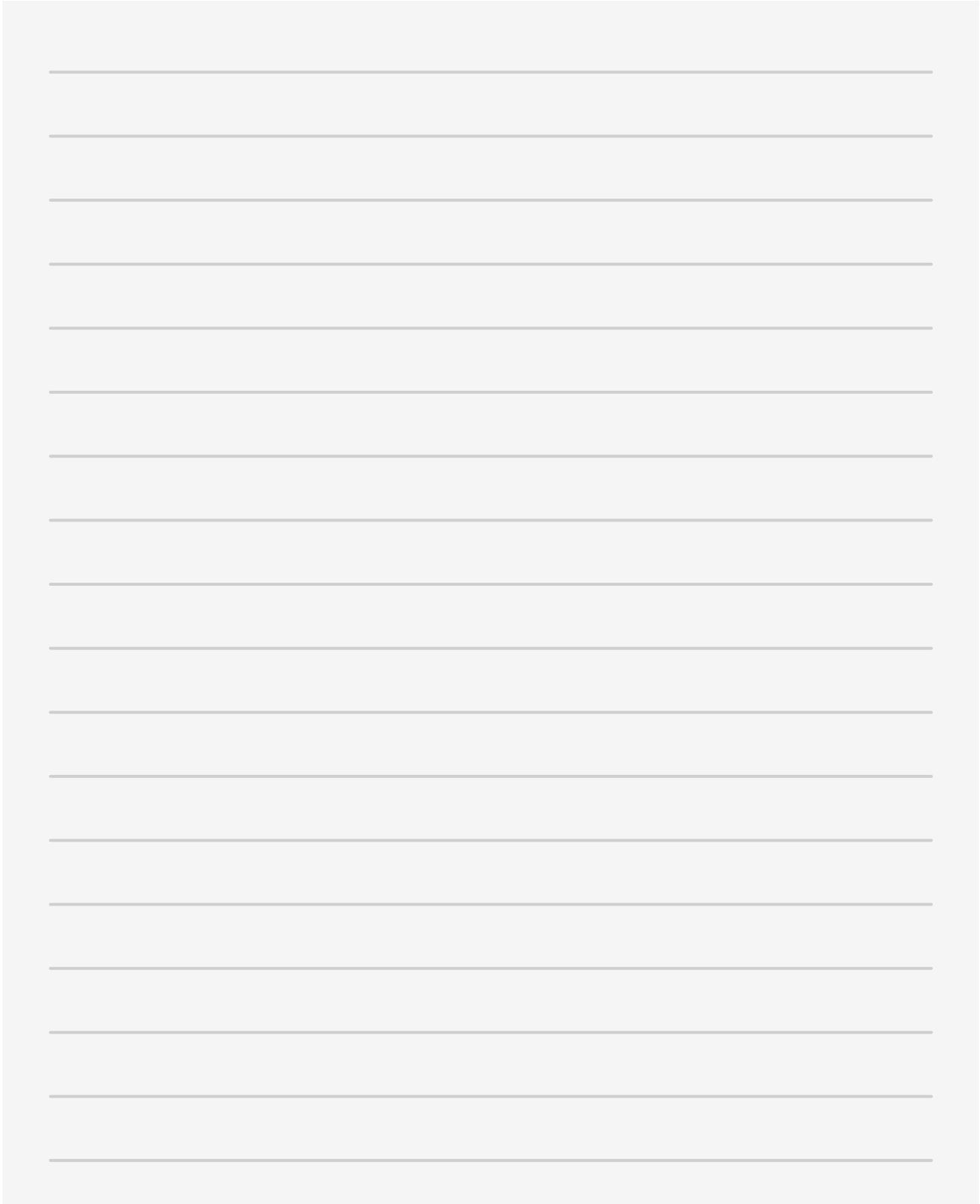
# *Reflections on Chapter Eight*

## ENDINGS AND BEGINNINGS

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# *Reflections on Chapter Eight*

## ENDINGS AND BEGINNINGS



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## FINAL REFLECTION

I wish you strength, a supportive circle, and the certainty that your well-being matters as you carry on in this Parkinson's Life.

*Terri*



## MEET TERRI

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Learn more at

[seaburyhouse.com](http://seaburyhouse.com)

Terri Pease Ph.D. is a highly experienced professional in the social services and healthcare industries who has dedicated her working life to helping people who are facing highly stressful situations. She has trained staff in organizations around the United States on offering supportive, empathic, and effective trauma-informed care to those who need it most.

When Terri married her husband, diagnosed with Parkinson's Disease before they met, she brought her confidence and a wealth of knowledge and experience to bear on caring for him.

Her professional experience has informed her approach to caregiving and to encouraging Parkinson's caregivers to caregivers to make self-care real, practical, and possible.



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"Sometimes the  
smallest step in the  
right direction ends  
up being the biggest  
step of your life."

MARY ANN RADMACHER

# OTHER RESOURCES

*After you have read Love, Dignity and Parkinson's, you may want to have a day-to-day message from Terri, helping you to move forward to a new vision of your caregiving life.*

*Join the other caregivers who have found that the Parkinson's Caregivers Reset and Refresh program gave them a new vision of themselves and led to an easier and happier connection with their PWP, their Partner with Parkinson's, and with themselves as well.*

*To find out more go to [XXXXXX insert link here](#).*

*And visit my website [www.seaburyhouse.com](http://www.seaburyhouse.com) to find a growing list of products, all designed to make caregivers' self-care real, practical, and possible.*