

COURAGE *for* CAREGIVERS
A RETREAT PARTICIPANT WORKBOOK
————— IN COMPANY WITH —————
HENRI J. M. NOUWEN

MARJORIE J. THOMPSON



An imprint of InterVarsity Press
Downers Grove, Illinois



InterVarsity Press

P.O. Box 1400 | Downers Grove, IL 60515-1426

ivpress.com | email@ivpress.com

©2022 by The Henri Nouwen Legacy Trust and Church Health Center of Memphis Inc. Material written by Henri Nouwen © Henri Nouwen Legacy Trust

All rights reserved. No part of this book may be reproduced in any form without written permission from InterVarsity Press.

InterVarsity Press® is the publishing division of InterVarsity Christian Fellowship/USA®. For more information, visit intervarsity.org.

Scripture quotations, unless otherwise noted, are from the New Revised Standard Version Bible, copyright © 1989 National Council of the Churches of Christ in the United States of America. Used by permission. All rights reserved worldwide.

While any stories in this book are true, some names and identifying information may have been changed to protect the privacy of individuals.

The publisher cannot verify the accuracy or functionality of website URLs used in this book beyond the date of publication.

Contents

INTRODUCTION	5
RETREAT SCHEDULE	7
SESSION 1— <i>The Mutuality of Caregiving: Henri's Wisdom and Our Stories</i>	9
SESSION 2— <i>The Challenges of Caregiving: Naming and Embracing</i>	21
SESSION 3— <i>The Gifts of Caregiving: Seeing and Celebrating</i>	39
SESSION 4— <i>The Sustenance of Caregiving: Self-care and Spiritual Practice</i>	55

Introduction

WELCOME TO **COURAGE FOR CAREGIVERS**, a retreat created especially for individuals in an active season of caring for a family member or other individual in ways that stretch beyond the demands most of us would expect to encounter as we move through the stages of our lives. You may be caring for a child with special needs. Your child may even be an adult in chronological years yet still require close caregiving. Perhaps a family member suffers from a chronic or lengthy illness, whether physical or mental in nature. An accident or a stroke might have changed the vision of your future in an instant, thrusting you into a role you never expected and for which you felt unprepared. Perhaps your spouse's health has taken a turn that reminds you every day of the promise you made, "in sickness and in health." You may be caring for aging parents or in-laws, whether in your home or through frequent visits, necessary decisions, and advocacy to sustain comfort and quality of life as they live in their own homes or a nearby senior community.

Each of you gathered for today's retreat has your own story, but you are all caregivers. Here you will find that you are not alone, not misunderstood. You are with kindred spirits who also have chosen to draw away from circumstances that can be overwhelming in order to find space for reflection and renewal. You may wonder how the person you care for is doing in your absence. That's normal. Be assured that you have made a courageous decision to give yourself the gift of retreat, and are to be commended for this act of self-care! Today is about caregiving stories—the wisdom they hold, waiting

to be discovered, along with the confidence to embrace our stories and how they shape our lives both as caregivers and care receivers.

The retreat and workbook are structured around four sessions. We hope you'll think of this workbook not only as a place to keep notes about ideas or information that may be new to you, but primarily as a way to process your unique caregiving story—a journal of sorts that you can come back to repeatedly. You'll see many spaces where you are invited to write your thoughts about how concepts, quotes, and the experiences of others intersect with your own story. But please don't expect to fill all these spaces to your satisfaction in one day! Some will resonate more than others. Some you may want to think about more deeply and return to later. Some may simply be for another time in your life when your heart is ready.

The day will bring a mix of opportunities to reflect personally, share your stories with a small group, and hear the voices of others who know both the challenges and gifts of the journey you are on. At the end of the day, you will have the opportunity to glean key insights or a new practice to carry out with you as you return to your caregiving responsibilities and routines. We pray you will leave today refreshed in heart, supported in friendship, and strengthened in your own courage for caregiving.

RETREAT SCHEDULE OVERVIEW

- 8:30 Registration with Coffee, Tea, and Light Snacks
- 9:00 Welcome, Announcements, and Morning Prayers
- 9:20 *Session 1—The Mutuality of Caregiving:
Henri’s Wisdom and Our Stories*
- 10:00 *Break*
- 10:10 *Session 2—The Challenges of Caregiving:
Naming and Embracing*
- 12:00 *Lunch*
- 1:00 *Session 3—The Gifts of Caregiving:
Seeing and Celebrating*
- 2:30 *Break*
- 2:40 *Session 4—The Sustenance of Caregiving:
Self-care and Spiritual Practice*
- 3:45 Evening Prayers
- 4:00 *Goodbyes*

SESSION
1

The Mutuality of Caregiving

HENRI'S WISDOM AND OUR STORIES

SESSION 1

The Mutuality of Caregiving: Henri's Wisdom and Our Stories

HENRI NOUWEN— OUR SPIRITUAL COMPANION

HENRI NOUWEN—beloved spiritual writer, teacher, and pastor—will be our primary spiritual guide as we wrestle with the challenges and identify the joys of caregiving. Henri had much to say on the subject of care across the arc of his ministry. A Dutch Catholic priest who reached across denominational boundaries, he touched the hearts of people worldwide. His humility and vulnerability revealed our shared humanity. Deeply conscious of his own weakness, limitation, and longing, he gave powerful witness to the grace of God's infinitely tender love for all. Henri was not afraid to acknowledge the “dark night” of our human journeys, nor was he shy to proclaim the great hope and joy of our faith.

CAREGIVING IS UNIVERSAL

Caring is the privilege of every person and is at the heart of being human.

—HENRI NOUWEN, *OUR GREATEST GIFT*

Noting connections to my story...

To care is the most human of all gestures.

—HENRI NOUWEN, *CARE AND THE ELDERLY*

Noting connections to my story...

THREE KEYS TO HENRI'S PERSPECTIVE ON CARE

1. _____

2. _____

3. _____

AUTHENTIC CARE

In contrast to cure, Henri lifts up the beauty and pain of authentic care:

What is care? The word finds its origin in the word kara, which means to lament, to mourn, to participate in suffering, to share in pain. To care is to cry out with those who are ill, confused, lonely, isolated, and forgotten, and to recognize their pains in our own heart. To care is to enter into the world of those who are broken and powerless and to establish there a fellowship of the weak. To care is to be present to those who suffer, and to stay present, even when nothing can be done to change their situation.

—HENRI NOUWEN, *A SPIRITUALITY OF CAREGIVING*

Noting connections to my story...

HENRI'S WISDOM ON COMPASSION— OURS AND GOD'S

Compassion is hard because it requires the inner disposition to go with others to the place where they are weak, vulnerable ... and broken. But this is not our spontaneous response to suffering. What we desire most is to do away with suffering by fleeing from it or finding a quick cure for it.

—HENRI NOUWEN, *A SPIRITUALITY OF CAREGIVING*

Noting connections to my story...

Faith in relation to suffering:

There can be no human beings who are completely alone in their sufferings since God, in and through Jesus, has become Emmanuel, God with us. It belongs to the center of our faith that God is a faithful God, a God who did not want us to ever be alone, but who wanted to understand—and stand under—all that is human. The Good News of the Gospel, therefore, is not that God wanted to take our suffering away, but that God became part of it.

—HENRI NOUWEN, *THE ROAD TO PEACE*

Noting connections to my story...

Deep mutuality:

Henri teaches that deep mutuality lies at the heart of every caring relationship.

In the very act of caring for another, you and I possess a great treasure. ... Caregiving carries within it an opportunity for inner healing, liberation, and transformation for the one being cared for and for the one who cares.

—HENRI NOUWEN, *A SPIRITUALITY OF CAREGIVING*

Noting connections to my story...

Henri's story with Adam:

Eventually I found myself confiding my secrets to him, ... telling him about my frustrations, ... and my prayer life. What was so amazing ... was the gradual realization that Adam was really there for me, listening with his whole being and offering me a safe place to be. ... Adam was becoming my teacher, taking me by the hand, walking with me in my confusion through the wilderness of my life.

—HENRI NOUWEN, *A SPIRITUALITY OF CAREGIVING*

Noting connections to my story...

Those who ask for care invite us to listen to our own pains, to know our own wounds, and to face our own brokenness.

—HENRI NOUWEN, *A SPIRITUALITY OF CAREGIVING*

Noting connections to my story...

OUR STORIED LIVES

Stories are essential to our understanding of human life. They help us make sense of the narrative of our own lives. Jesus was a consummate storyteller, capable of conjuring up a parable on the spot to bring a spiritual truth to life in the hearts of his hearers. Most of us are familiar with Jesus' greatest parables, like the Good Samaritan and the Prodigal Son. Yet all his parables pointed people to deep truths about God's character and kingdom. The most powerful human stories keep working in our hearts over time. Some become beacons of light for a lifetime.

YOUR CAREGIVING STORY

We do not always think of our life experience as a story. Yet our stories of caregiving are important to self-understanding and central to this retreat. Here is a simple way to begin thinking about the contours of your care story.

1. For whom do you offer care, and for how long thus far?

2. What is the primary setting for your caregiving?

3. Who are the main characters in this story?

4. If you were writing your story, what would be three main headings?

SESSION
2

The Challenges of Caregiving

NAMING AND EMBRACING

SESSION 2

The Challenges of Caregiving: Naming and Embracing

HENRI HAS MUCH TO SAY about the mutuality that lies at the heart of care relationships. He clearly sees challenges on both sides:

Many of us know from experience how hard it is to simply be a caregiver. At the same time, we may need to be reminded of how hard it is to be cared for. It isn't easy either way!

Noting connections to my story...

Anyone involved with intense or long-term care knows just how difficult and complex it can be. As you listen to the stories presented now, and the challenges they illustrate, notice where they connect with your own story, and how they shed new light on your experience.

COMMON CHALLENGES

Following are five categories of challenge common to caregiving. Ponder how you experience and see these—on both sides of your care relationship.

Physical challenges: difficulties or disabilities of the person you care for; the physical stresses you experience as a consequence of giving care; cumulative strain of long-term caregiving as a loved one's needs increase; the physical complications of caring from a distance, including travel.

Noting connections to my story...

Emotional challenges: grief over lost freedom, autonomy, dreams, or facing into impending death; anxiety over loved one's condition, financial depletion, or what the future holds; feeling inadequate and questioning self-worth; frustration at limitation; conflict between love and resentment; guilt and shame; depression from feeling totally overwhelmed, isolated, or unsupported as a caregiver; feeling lonely, useless, or hopeless as a care receiver.

Noting connections to my story...

Mental challenges: disability or deterioration of brain function; difficulty with communication or behavior patterns; mental fatigue or “brain fog” from physical exhaustion or unrelenting repetitive tasks; learning curve of medical jargon and home medical routines; demanding process of learning what your loved one needs beyond medical care to thrive; keeping your mind active in other spheres.

Noting connections to my story...

Balancing tensions gracefully: giving a loved one as much freedom and respect as possible, while needing to take “parental” responsibility for their care; balancing needs of care receiver with needs as caregiver; balancing care needed by one family member with that of other family members; balance between work, home, friends, spiritual community.

Noting connections to my story...

Spiritual challenges: living with unanswered questions; keeping faith, hope, love alive; letting go of control and surrendering to God; embracing rather than resisting the hard realities; choosing the “unchosen” circumstance we are given; being at peace in the face of loss; seeing Christ in the face of our care receiver (or caregiver) and others involved in the care situation.

Noting connections to my story...

NAMING OUR CHALLENGES HONESTLY

It is important to recognize clearly and speak honestly what we find most challenging, painful, or difficult in our caregiving story. Until we allow, and own, and name our real feelings, we cannot take the next step of fully accepting and even embracing these challenges. This truth telling also gives us the opportunity to see more clearly where we might need to ask for support.

Noting connections to my story...

On mixed feelings and motivations, Henri candidly acknowledges,

If the one we care for is a family member, we also may bear all the conflicting emotions of trying to support a loved one. On the one hand, there is the desire and willingness springing from our love for this person. On the other hand, our desire and willingness may be woven together with loneliness, resentment, guilt, and shame for unwanted thoughts and dreams of being free once more from the burden of care.

—HENRI NOUWEN, *A SPIRITUALITY OF CAREGIVING*

Noting connections to my story..

Conflicted feelings can coexist in close quarters! We may feel authentic love while personally attending to our loved one's needs *and* resentful duty when those needs interrupt other important tasks and relationships.

Noting connections to my story...

There is often a huge cost to the caregiver, and sometimes the care we give springs not from a well of love and altruism but from a bitter sea of resentful duty and obligation.

—HENRI NOUWEN, *A SPIRITUALITY OF CAREGIVING*

Noting connections to my story...

CHALLENGES FOR THE CARE RECEIVER

Being the person on the receiving end of care is full of hardship as well. As caregivers, how do we attend to the suffering not only of physical or intellectual decline, but emotional and spiritual pain in the hearts of those we care for? Henri speaks directly to some of these challenges:

Important for us as caregivers to remember here is that it is embarrassing to be exposed in weakness and to need help. Having managed their own lives so easily for so long for both themselves and others, those who are ill or weak may find it humiliating to have to receive care and ask someone else to help them, especially if the one asked is already busy and occupied with important matters.

Another very real sorrow for those receiving care is that it is not easy to wait—sometimes in pain—for someone to do for them what they can no longer do for themselves. It is bad enough for them to feel so fragile and so scared, but worse still to have to trust someone else—someone they may not know at all and who never knew them when they were strong. It can be humiliating to allow a stranger or even a family member to enter their intimate, physical, and private space. In other words, it is miserable for them to feel that they are the powerless one in the carer/cared-for relationship.

—HENRI NOUWEN, *SPIRITUALITY OF CAREGIVING*

Noting connections to my story...

MORNING PERSONAL REFLECTION ACTIVITY (20 MINUTES)

Read through the questions, and respond first to those that most draw your attention. You may need to come back to other questions later.

As I ponder the categories under “Common Challenges,” which aspects of each resonate with my experience? What would I name as the three greatest challenges in my caregiving story?

In what ways are my feelings about caregiving mixed?

What might it feel like to embrace the parts of it I most resist?

In which areas of challenge do I most need support? How am I reluctant or ready to ask for help?

How many of my care receiver's challenges can I name?
What else might my care receiver be experiencing that I tend not to see?

QUESTIONS TO CARRY INTO MY LIFE FROM THE MORNING SESSION

Where have I experienced the “cure versus care” mentality—in health care professionals, or friends and family members, or in myself?

When does compassion feel natural to me in caregiving?
When is it hard? What do I notice about myself as I look at my responses?

What are some of the painful “Why?” questions in my caregiving story?

How does my faith bring a sense of comfort or meaning in the face of suffering—my own and others’?

How might I choose to face pain or difficulty with courage, hope, even curiosity?

Is there a way for me not simply to *endure* but *embrace* the challenges?

What can I learn, here and now, that serves my growth in love?


SESSION
3

The Gifts of Caregiving

SEEING AND CELEBRATING

SESSION 3

The Gifts of Caregiving: Seeing and Celebrating

 **OUR CARE RELATIONSHIP** is never a one-way street. Mutuality becomes meaningful as we recognize the *gifts* received while caring for others. Yes, caregiving may bring heartache and hardship, but it is also a sacred privilege!

In opening our hearts to God and others, we begin to see how much we receive in giving. The reason, spiritually speaking, is simple: each of us is imprinted at our core with the divine image, however dim or distant it may seem. Deep in the heart of each person dwells an imperishable glory, freely given to us and cherished by our Creator beyond our wildest imagining! God loves us with an everlasting love not because we are “good” or even making progress toward goodness, but because we belong to God who chooses to belong to us.

Henri never ceased to proclaim that we are all beloved children of God: “At the core of my faith belongs the conviction that we are the beloved sons and daughters of God. And one of the enormous spiritual tasks we have is to claim that and to live a life based on that knowledge.”¹ Our belovedness does not depend on our status or accomplishments or wholeness. In the economy of Grace, the least among us—the sick and forgotten, the weak and vulnerable, the disabled and frail—are precisely the ones God works through most powerfully. Henri says: “Every person is an unrepeatable expression of God’s creative grace. God can minister through anyone, and often does so in and through the least, the little ones, the handicapped, the poor, the unimpressive.”²

Noting connections to my story..

STORIES OF GIFT

A STORY WITH JEAN

JEAN LIVED WITH US FOR 20 months, longer than expected. After a year, when she expressed sorrow to be a burden in our lives, I could candidly say: “Yes, there is a burden in your care, but even more it is a great joy to have you with us and I wouldn’t have it any other way!” I did not deny that we felt a burden in caring for her. Jean could see my fatigue and was always an ace at detecting a white lie! But being honest about the hard side allowed her to hear equal truth in the happy side: my assurance that I *wanted* to be her primary caregiver at the end of her life, and found fulfillment in that choice because of who she was and what she meant to me.

Jean had no fear of what lay on the other side of death. While she was not looking forward to the final act of dying, her faith was strong and her trust in the reality of the communion of saints was a blessing. I knew she suffered no needless anxiety, but rather carried a spirit of inner peace. Our shared faith was a great gift to me, especially when I felt anxious or grieved about her suffering.

Above all we were aware of the gift of one another’s presence. Jean was present for all our family celebrations—if only standing at the loft railing looking down, tethered to her oxygen tubes. With her presence came warmth, vitality, and her sardonic wit—bringing smiles and much-needed levity. I will never forget the last exchange between my mother and mother-in-law, Bab, the day the ambulance came to take my mother to the Hospice Residence. Bab, never comfortable with finalities, put on an unconvincing smile and said, “Oh Jean, I hope we will see you back here again very soon!” Jean—who had to gasp for air every

few words—retorted in her gravelly voice, “Well, don’t hold your breath!” Bab could not grasp the ironic humor, but John and I barely contained an outburst of hilarity.

What responses arise as I read this story? How does my story connect or differ?

A STORY WITH BAB

MY RELATIONSHIP WITH Bab was complicated, and it took time for me to recognize the gifts in her care. But the more I learned about her stern upbringing and her father's harshness, the more I saw her inner wounds. She had not received affirmation or emotional warmth as a child, and did not know her belovedness.

Bab had taught Sunday school children about God's love but couldn't trust that love for herself. I began to recognize a tug in my heart to show her more tangible affection—to express that she was loved just for who she was. She needed concrete evidence, the very physical expressions of love she appeared determined to repel. I decided simply to plant a kiss on her cheek every time I said, "Good night." Before long, Bab showed clear signs of looking forward to that kiss. And if it appeared I might be about to forget, she would tap her cheek to remind me! This soon became an unalterable ritual—first just between the two of us, until gradually John was drawn in as well.

Over time, Bab began to believe me when I said—along with that kiss—"I love you, Bab." It was easier for me to show Bab tender gestures of love than it was for John, who grew up with the wounding effects of an emotionally distant mother. Freedom from the tangled web of family history was one of the great gifts in my role as daughter-in-law. I am happy to report that my freedom had positive ripple effects in John and Bab's relationship.

Bab was my unwitting teacher. She kept me humble by revealing me to myself—my reactions, unrealistic expectations, ego needs, fear and anger. In her maddening stubbornness, she showed up my inability to fix, change, or control others to my liking. Bab gave me plenty of grist for growth. She drove me daily to prayer and my great need for the Spirit of grace!

Henri's friend Parker Palmer often said, "Sometimes we don't think our way into a new way of living, we live our way into a new way of thinking."

What responses arise as I read this story? How does my story connect or differ?

GIFTS FROM OUR CARE RECEIVERS

The bodily resurrection of Jesus is the most profound basis for the sacredness of all human flesh and the most compelling argument for reverencing all forms of life. ... Washing, dressing, feeding and supporting deeply handicapped people is a holy vocation when we know that their bodies, like ours, are destined to share in the resurrection of Jesus.

—HENRI NOUWEN³

Noting connections to my story...

What could be more precious than to see the face of our humble Lord shining in the flesh and bone of another human being, weak and imperfect as we all are? What better gift could there be in this world?

Noting connections to my story...

Care receivers give gifts as well. Jean and Bab embodied a beautiful insight Henri articulated this way:

Our weakness and old age call people to surround us and support us. By not resisting weakness and by gratefully receiving another's care we call forth community and provide our caregivers an opportunity to give their own gifts of compassion, care, love and service. As we are given into their hands, others are blessed and enriched by caring for us. Our weakness bear fruits in their lives.

—HENRI NOUWEN⁴

Noting connections to my story...

AFTERNOON REFLECTION ACTIVITY OPTION 1

Questions for Personal Reflection (20 minutes)

Respond first to those questions that most attract your attention.

Where in your care relationship have you known mutuality in *blessings* given and received?

What are some gifts you have discovered in the act of offering care?

Can you name a moment when you truly felt that your caregiving was a “sacred privilege”? If so, how did that recognition affect you?

How do you receive the truth of your belovedness in God’s eyes? In what ways does your sense of being or not being beloved affect the way you see your care receiver?

How has your care receiver been a teacher to you?

AFTERNOON REFLECTION ACTIVITY OPTION 2

Letter of Appreciation

Your second option for the afternoon reflection time is to write a letter of appreciation to a loved one for the blessings received in caring for him or her.

Henri Nouwen was a prolific letter writer. He kept up an amazing volume of correspondence with hundreds of individuals over his lifetime. Some were ordinary letters to family or friends, but many were letters of spiritual guidance and support written to people struggling with painful questions and circumstances.*

It is rare that people today take time to write letters by hand. Yet writing a letter can be a fine way to express your own feelings and process your caregiving story. Letters to family and close friends are not usually formal compositions, but rather spontaneous expressions of what we are experiencing and thinking. Like personal journals, they don't need to be grammatically correct or even written in complete sentences!

Use the space provided here to write either a few notes about what you would like to express in a letter you will write when you have more time or a short draft of a letter that you can copy onto a card or paper you think might be meaningful to the person receiving your letter.

*An entire volume of Henri's letters has now been published in a book, *Love, Henri*. The title reflects how he signed his name. *Love, Henri*, copyright by The Henri Nouwen Legacy Trust, was published by Convergent Books, an imprint of Crown Publishing Group, in 2016.

My letter of appreciation...

SESSION

4

The Sustenance of Caregiving

SELF-CARE AND SPIRITUAL PRACTICE

SESSION 4

The Sustenance of Caregiving: Self-care and Spiritual Practice

CAREGIVING IS A complex mix of challenge and gift, exhaustion and fulfillment, grief and joy. How will our caregiving be sustained? This question raises the issue of self-care. We are pulled in opposite directions between giving ourselves to the care of others and taking time for adequate self-care. How can a realistic balance be achieved between two necessities in constant tension?

Western culture has burdened us with the idea that caring for ourselves is somehow selfish. One of Henri's friends offers a healthier and more realistic perspective:

Self-care is never a selfish act—it is simply good stewardship of the only gift I have, the gift I was put forth on earth to offer others. Anytime we can listen to true self and give the care it requires, we do it not only for ourselves, but for the many others whose lives we touch.

—PARKER J. PALMER, *LET YOUR LIFE SPEAK*¹

Noting connections to my story...

When we are exhausted, the care we offer others suffers as well. And God does not require us to ruin our health to prove our love. Jesus models balance when he withdraws from the crowds to take time apart for prayer and inner renewal.

Noting connections to my story...

THE TENSIONS OF SUSTAINABLE CARE

What feelings arise when others urge me to “take care of myself”? Do I feel that I am worthy to be cared for by others? Am I worth caring for myself?

What makes self-care most difficult for me? What is hardest for me to hear in this topic of self-care?

SELF-CARE PRACTICES

Self-care is an intentional way of living where our values, attitudes and actions are integrated into our day-to-day routines, not one more thing to add to our growing “to do” lists.

—MICHELLE O’ROURKE²

Noting connections to my story...

Donna, mother to Nicholas—a high-needs medically fragile son—has been rethinking self-care: “What if every caring action we perform for somebody else could be an opportunity to do something for ourselves too?” For example: “When I get someone a cup of tea, make myself a cup as well. If I feel cold, I put a sweater on my son—why not on me too? It means being mindful about how to care for yourself as you care for another.” Donna communicated to her whole family expectations of loving behavior, including their nurture of her. “Even Nicholas,” she laughed. “I would say to him, ‘I need a hug’ or ‘I know you have a lot to give the world, and the world includes me.’ I refused to be invisible to those I was looking after.”

In what ways do you already integrate self-care into your daily routines?

Imagine two ways you could be mindful of self-nurture as you care for another person.

How do you express your need for nurture to family members or friends?

Donna suggests you choose three things you typically do in a week that you would love to give someone else—yard work, grocery shopping, light housekeeping? Think of who is in your literal or metaphorical “neighborhood.” What are others gifted with or interested in, and how might you give them an opportunity to contribute to your need for support?

What three tasks would I love to delegate to others?

Who in my “neighborhood” might like to help me, and in what way?

TWO IMPORTANT QUESTIONS

Michelle O'Rourke, a palliative care nurse, offers practical help on issues of self-care. She starts with two questions:

1. Who holds you? (Who cares for you? Who carries the burden with you?)
2. "What refreshes you?" (We have different needs; what are yours?)

Here is her list of self-care suggestions for caregivers:

- Take stock of what's on your plate. Prioritize, delegate, be selective.
- Find time for yourself every day—quiet, unplugged time.
- Identify what renews you and build it into your schedule.
- Enjoy nature and the arts.
- Enjoy family and friends.
- Keep a sense of humor.
- Remember to play!
- Reflect on what you have given and received.
- Tend to your spiritual needs—cultivate an inner life.³

Which of these are most life-giving to you? Which do you already practice in some measure? Which do you most crave but feel are out of reach? What would you add?

Noting connections to my story...

Michelle's first point allows you to set some boundaries that open up much-needed space for self-care. Prioritizing and delegating are not easy. This may be a good area to discuss with a wise friend, counselor, or more experienced caregiver.

Henri Nouwen describes burnout as “giving without receiving.” He makes five points on avoiding burnout as a caregiver:

- It is important not to be alone in caring, and to be aware of your limits.
- Realize when you need “time out” or a change, and don't feel guilty about it.
- It is important to be cared for yourself—where do you find support?
- Trust that when you leave, your presence will continue.
- To be a good care partner is to be really present.

Noting connections to my story...

Henri tells us the most difficult thing is to be only half there—to be present without wanting to be, which leads to resentment.⁴ When we resist being fully present in our care relationships it adds a level of needless fatigue. As we yield resistance and allow ourselves to dwell in the “here and now” of care, stress is actually reduced!

Noting connections to my story...

REALISTIC SPIRITUAL PRACTICES

What spiritual practices are realistic for us as caregivers, given our limited time and energy? The practices suggested here are selected to fit the realities of caregiving. They can help lighten our load by releasing heavy emotions, opening up limited perspectives, attuning our listening skills, and simplifying our prayer life. As with self-care, choose the spiritual practices that suit your circumstances and nourish your heart.

1. HONEST LAMENT: PRAYING THE PSALMS

Before we can embrace the difficult circumstances in our lives, we need to lament them. Scripture gives us permission to express the full range of human emotions. We see this most fully in the Psalms, where praise and grief, joy and sorrow, contentment and fury contend on every page—even in the same psalm!

One helpful practice is “Praying the Psalms”—in this case psalms of lament. Select a psalm that expresses sorrow, anguish, incomprehension, or rage (“enemies” can be understood as what we are at war with in our own divided hearts).

A few psalms to consider:

- Psalm 13 (“How long, O Lord?”)
- Psalm 22 (“My God, why have you forsaken me?”)
- Psalm 42 (“My tears have been my food day and night.”)
- Psalm 69 (“Save me, O God, for the waters have come up to my neck.”)
- Psalm 77 (“Has God forgotten to be gracious?”)
- Psalm 88 (“O Lord, why do you hide your face from me?”)

Perhaps only a few phrases or stanzas will speak to your life. Let the psalmist’s cry resonate in your own weary, wounded soul. Personalize the ancient words, bringing your experience and feelings into it. You may paraphrase an existing psalm, or simply write your own from scratch. Here is a sample paraphrase of Psalm 13:

How long, O Lord, must we keep this up? Forever?

How much longer can I take the stress, the unknowing, the
endless care?

How much longer must I endure watching her suffer and
shrivel by inches?

My soul cries out within me for help and comfort!

Look and answer me, O Lord my God!

Give me some hope, or I will sleep the sleep of death soon myself.
I put my trust in your saving help and love, O Lord.
Do not abandon me!

2. REFRAMING

Many practices can sustain our caregiving that do not require stretches of time apart. One of the most helpful is to reframe our experience. As we go through life we turn it into a story, creating an internal narrative based on our perceptions and assumptions. We are largely unaware of these deeply held assumptions and interpretations. Gaining new perspectives can give us a different frame of reference and thus a new story line.

“A Story with Bab” tells how the author put a different frame around Bab’s emotional distance when she could see it as an expression of fear and awkwardness, instead of as her being incapable of affection. We so easily misinterpret another’s thoughts and feelings.

Henri used to get frustrated by what he felt were constant interruptions of his work from phone calls or students knocking on his door. One day, he suddenly realized that “the interruptions” *were* his work! This reframing of his experience significantly reduced his frustration levels.

How might it change our view if we thought of our care receivers as souls who are offering themselves to us, in great vulnerability, for the sake of our own spiritual growth?

How did Jesus change the frame of peoples' assumptions in his teaching and healing work?

3. HOLY LISTENING

Listening becomes a spiritual practice when we discover it as sacred ground. Caregiving is a tremendous opportunity to learn how to listen more deeply to ourselves, to others, and to God.

Noting connections to my story...

Listening fully to others is a sacred art, one of the deepest expressions of human care we have at our disposal. Sometimes it is the gift we most need, for to be truly heard is not only comfort but also affirmation of our dignity and value. In caregiving we often don't know how to be of greatest help, especially when we can do little to alleviate another person's suffering. It is freeing to discover that simply being a listening presence for our care receiver may be the best gift we can offer.

Noting connections to my story...

4. SIMPLE PRAYERS

What makes listening a holy act is recognizing divine presence at the heart of everything. Listening to God in the midst of daily challenge and gift is the crux of prayer. Some ways of prayer are easy to integrate into ordinary life.

Breath Prayers. One way to practice Breath Prayer is to form a very short prayer phrase in two parts that correspond to the in- and out-breath:

- “Holy Spirit, fill me.”
- “Heal my heart, gracious God.”
- “Oh Lord, give me patience.”

Spend a few minutes breathing your prayer before you rise from bed, breathe it as you shower or gaze out a window, call it to mind in times of stress, offer it up before drifting off to sleep. Depending on ability, invite your care receiver to find a meaningful Breath Prayer and promise to pray it with them. Share your prayer and ask them to pray it with you. This can be a beautiful expression of mutual care!⁵

Scripture Phrase Prayers. A form of prayer many of us do naturally takes short verses of Scripture as a focal point. We each have our favorites:

- “Be still and know that I am God” (Psalm 46:10).
- “In quietness and trust shall be your strength” (Isaiah 30:15).

Here are a few such prayers I drew from Ephesians 4:29–5:2 and Colossians 3:12–17.

- “Put away all bitterness, wrath, and anger.”
- “Be kind, tenderhearted, forgiving one another.”
- “Clothe yourself with compassion, kindness, humility, and patience.”
- “Bear with one another.”

Henri says that when we spend a little time each morning “sitting in the presence of God with the words, ‘The Lord is my shepherd,’ they may slowly build a little nest for themselves in our heart and stay there for the rest of our busy day.” Repeating

these verses is less an occasion to ponder their meaning than to create inner space for Presence.

Noting connections to my story...

5. AFFIRMATIONS

An affirmation expresses deep confidence in who we are before and in God. It is a declared spiritual truth that can keep us grounded, hopeful, and steady when life is difficult and the road is long. One of the great truths Henri discovered and claimed was his belovedness. Each of us is beloved in God's eyes. Here are a few sample affirmations, spoken to God:

- I am written on the palm of your hand.
- I am your beloved and precious child.
- You are faithful and will never let me go.

Write your affirmations on sticky notes and place them where you will see them daily—atop your dresser, on a mirror, beside

your breakfast placemat, or on the edge of your computer. Like Breath Prayer, the practice of affirmation is wonderful to share with care receivers. Each of you can benefit from your own affirmations, and when you know which ones are meaningful to each other they become another bond between you. You may find yourself reminding the other, when they have forgotten, of their phrase of confident trust or beloved identity.

Noting connections to my story...

6. BLESSINGS

The Jewish practice of parents blessing their children at the weekly celebration of Shabbat is moving. What a lovely thing to learn how to bless one another—a God-given power each of us may claim to invoke goodness and grace for others. When we bless each other we say good words: words of gratitude, affirmation, and encouragement; words that draw attention beyond ourselves

to the realm of divine presence. The way you express it will be uniquely yours. Perhaps you rest a hand on another's shoulder, or take their hands in yours, meet their eyes, and speak simple, heartfelt words like these:

- “You are a great gift to me, and I love you dearly.”
- “I bless you for your patience with me, and your trust in my care.”
- “You are so dear to me. May God comfort and fill you with all peace.”
- “Your inner strength is a witness to me, and I bless you for who you are.”

Or you could memorize a few blessings from Scripture:

- “The Lord bless you and keep you; the Lord make his face to shine upon you and give you peace.”
- “May God give you a quiet night and peace at the last.”

Such blessings name the divine presence we place our trust in both here and beyond this lifetime. For those who are facing death, a bedtime blessing like this can help prepare their spirit for its coming transition to the fullness of the kingdom.

You may find that the one you care for would like to bless you in return, confirming a joyful, tender mutuality in your relationship. Receive gratefully!

[Noting connections to my story..](#)

7. SELF-COMPASSION

As caregivers we often wonder if we are giving all we should or doing so in the best way. We may carry unrealistic expectations of trying to be perfect. When we feel inadequate or guilty about some failure—real or perceived—it is time for self-compassion.

Self-compassion is a practice of mindfulness. Negative self-talk is the bell calling us to be aware of self-recrimination:

- “I just don’t have what it takes to do this.”
- “I was so impatient with him, he must hate me.”
- “Why can’t I just say this honestly? I’m such a wimp!”
- “How could I have forgotten? What an idiot I am!”
- “God must think I’m a pretty poor specimen.”

We have choice words for ourselves, and sometimes use them as battering rams. Can we humbly allow for our human weaknesses? Do we affirm that God loves us even when we are fearful, frustrated, or foolish?

Noting connections to my story..

Self-empathy gives us the opportunity to listen to our own hearts with the same quality of compassionate attention that we would offer another in our best moments.

—DEBORAH HUNSINGER⁶

When you are worn out, frustrated with yourself, discouraged and dispirited, try this healing practice:

A MEDITATION FOR COMPASSIONATE SELF-OBSERVATION

Each of us has, deep inside, the capacity to see with eyes of compassion. Christ, who indwells our heart, sees with love. With a little intention and practice we can access our heart-center in daily life. Here is one way to practice compassion for ourselves.

Get in touch with something about yourself you really dislike and wish you could be rid of—perhaps a character weakness or bad habit. Become aware of your usual feelings in relation to this. Notice the feelings without sinking too deeply into them.

Now take a step back from your judging ego to a deeper center, a place of interior freedom from which you can observe your reactions and feelings. This is your inner sanctuary of love, where the compassionate Spirit burns like a little pilot light.

Breathe and relax into this heart-center. Just as oxygen feeds a flame, let your breath feed the Spirit-flame within, till it is full and bright. Feel compassion fill your heart.

From this compassionate center, look at the part of yourself you so dislike. What do you observe?

Let the compassionate One in your heart give comfort to the wounded child in you—with words, or song, or a gesture of embrace. Notice how your inner child responds.

Accept a higher love for yourself—even in weakness, brokenness, and incompleteness. You are a work in progress. Christ bears with you patiently.

Take a moment now to name and absorb fully the gift of this meditation.⁷

CONCLUDING THIS STRETCH OF THE JOURNEY

Our exploration of the story of caregiving through this retreat now comes to an end. Our stories will, of course, continue. Perhaps you have found new ways to give voice to your experience, and have made a start on telling your caregiving story. Hopefully you have a greater sense of community with others on this path, and some alternative perspectives on your care relationship. With renewed commitment to self-care and useful spiritual practices to help sustain you over time, may you feel fresh courage to move into God's future with your loved ones.

Naturally, the final word belongs to love. What else, finally, can we cling to? Is there any higher good, anything beyond the love of God? All our suffering, yearning, sacrifice and service; all our joy, gratitude, and growth toward maturity—it is *all* encompassed by God's love. When our loved ones die, and when we ourselves cross the threshold of death, we will find ourselves fully embraced in the Light that is simply the glorious radiance of divine Love. Even now each of us participates, in our small way, in the Love that will not let us go. What greater privilege and joy can there be? All blessings of grace and peace as you journey forward!

Endnotes

Session 3

1. From sermon, “Being the Beloved,” delivered 8/22/92 on the “Hour of Power” program.
2. From an audio-taped address titled “Caring,” Hilton Head Island Spiritual Formation Emphasis Week, Evening Community Session at St. Francis, 10/6/93.
3. From an unpublished journal entry dated 3/2/86 (in Robert Durback, *Seeds of Hope*, 1997).
4. From “The Path of Living and Dying,” in *Finding My Way Home*, p. 79.

Session 4

1. Parker J. Palmer, *Let Your Life Speak: Listening for the Voice of Vocation* (Jossey-Bass, 2000), 30.
2. Michelle O’Rourke and Eugene Dufour, *Embracing the End of Life: Help for Those Who Accompany the Dying* (Novalis Publishing Inc., 2012), 143. Emphasis added.
3. The two questions and first list are adapted from PowerPoint slides O’Rourke presents in her workshops. Used by permission.

4. The second list and point about presence are drawn from an interview with Henri Nouwen, University of Notre Dame Alumni, Continuing Education, April 3, 1996.
5. For more on Breath Prayer, see Ron DelBene, *Into the Light: A Way to Pray with the Sick and Dying* (Wipf and Stock, 2009).
6. Deborah Hunsinger, “Keeping an Open Heart in Troubled Times,” essay in *A Spiritual Life: Perspectives from Poets, Prophets, and Preachers*, Ed. Allan Hugh Cole, Jr. (WJK, 2011), 127.
7. “The Compassionate Observer” is a phrase coined by Jane Vennard. See *A Praying Congregation: The Art of Teaching Spiritual Practice* (Alban Institute, 2005, 99-100). These meditations differ significantly from Vennard’s original exercises. The borrowed phrase and a few of her images are used with Vennard’s permission.

*Works by Henri Nouwen used in
featured quotations in Courage for Caregivers:
A Retreat Participant Workbook*

Our Greatest Gift: A Meditation on Dying and Caring (HarperSanFrancisco, 1994), 51-52.

Care and the Elderly, pamphlet adapted from a speech delivered 6/6/75 (The Henry Nouwen Legacy Trust, 2008), p. 5.

A Spirituality of Caregiving (Henri Nouwen Legacy Trust, 2011), 16, 17, 19, 24-25, 26, 33, 38-39, 52.

“Christ of Americas,” (America Magazine, April 21 1984) in *The Road to Peace* (Orbis, 1998), 111.

BOOKS BY
Henri J. M. Nouwen

Adam: God's Beloved
Aging
Behold the Beauty of the Lord
Beyond the Mirror
Bread for the Journey
Can you Drink the Cup?
Clowning in Rome
Compassion
Creative Ministry
A Cry for Mercy
Encounters with Merton
Finding My Way Home
Finding Our Sacred Centre
The Genesee Diary
Gracias: A Latin American Journal
Heart Speaks to Heart
Here and Now
Home Tonight
In Memoriam
In the Name of Jesus
The Inner Voice of Love
Intimacy
Jesus and Mary
A Letter of Consolation
Letters to Marc About Jesus
Life of the Beloved
Lifesigns
The Living Reminder
Love, Henri: Letters on the Spiritual Life
Love in a Fearful Land
Making All Things New
The Only Necessary Thing
Our Great Gift
Out of Solitude
Path of Freedom
Path of Peace
Path of Power
Path of Waiting
Peacework
Reaching Out
The Return of the Prodigal Son
The Road to Daybreak
Sabbatical Journey
Seeds of Hope
The Selfless Way of Christ
Show Me the Way
A Sorrow Shared
A Spirituality of Caregiving
A Spirituality of Fundraising
A Spirituality of Living
Thomas Merton: Contemplative Critic
Walk with Jesus
The Way of the Heart
With Open Hands
With Burning Hearts
The Wounded Healer

Permissions

Grateful acknowledgement is made for permission to reprint the following excerpts from previously published works.

Excerpts from *A Spirituality of Caregiving*, by Henri J. M. Nouwen, copyright © 2011 by the Henri Nouwen Legacy Trust. Used by permission of the Henri Nouwen Legacy Trust. Published by Upper Room Books.

Excerpt from *Care and the Elderly*, by Henri J. M. Nouwen, copyright © 2008 by the Henri Nouwen Legacy Trust, is reprinted by permission of the Henri Nouwen Legacy Trust.

Excerpts from *Our Greatest Gift: A Meditation on Dying and Caring*, by Henri J. M. Nouwen, copyright © 1994 by Henri J. M. Nouwen. Reprinted courtesy of HarperCollins Publishers.

Excerpts from *The Road to Peace*, by Henri Nouwen. Maryknoll, New York: Orbis Books. Copyright © 1998 by the Henri Nouwen Legacy Trust. All rights reserved. Reprinted by permission of Orbis Books.

Excerpts from *Finding My Way Home*, by Henri Nouwen, copyright © 2001 by the Henri Nouwen Legacy Trust. Used by permission of the Crossroad Publishing Company.

Excerpts from *Seeds of Hope: A Henri Nouwen Reader*, copyright © 1997 by Robert Durback, is reprinted by permission of the Henri Nouwen Legacy Trust. Originally published in 1989 by Penguin Random House.

Excerpt from *Embracing the End of Life: Help for Those Who Accompany the Dying* by Michelle O'Rourke and Eugene Dufour, published in 2013, is courtesy of Novalis Publishing.

Excerpt from *Keeping an Open Heart in Troubled Times*, by Deborah Hunsinger, was published in *A Spiritual Life: Perspectives from Poets, Prophets and Preachers*, ed. Allan Hugh Cole Jr., 2011, and is courtesy of Westminster John Knox Press.

Excerpt from *Let Your Life Speak: Listening to the Voice of Vocation*, by Parker J. Palmer, published in 1999, is courtesy of Jossey-Boss Education Publishers, a Wiley imprint. Copyright 2000 by John Wiley and Sons, Inc. All rights reserved.

Henri J. M. Nouwen

MORE THAN 20 YEARS after his death, Henri Nouwen's life and writings on the spiritual life continue to touch millions of people in dozens of languages. Henri was born in the Netherlands in 1932 and was drawn to the priesthood in the Catholic church at a young age. After being ordained in 1957, he undertook further studies in psychology in the United States. In 1966, he accepted a position teaching psychology at the University of Notre Dame and wrote his first two books while there.

After doctoral studies, Henri spent ten years on the faculty of Yale Divinity School, where his classes were some of the most popular on campus. During these years he was also publishing prolifically. Later, Henri became interested in Latin America and the many poor affected by both political turmoil and theological developments. He considered living and ministering in Peru. Though he accepted a position on the faculty at Harvard, he remained restless and yearned for deeper meaning and personal connection with others. A chance meeting with Jean Vanier, the founder of L'Arche, an international movement of communities that welcome people living with disabilities, changed the path of Henri's life. He moved to Daybreak, a L'Arche community near Toronto in Canada. There he served in a pastoral role, gave countless talks and retreats, welcomed hundreds who sought counsel, and still found time to write, eventually publishing more than 40 books. At Daybreak he had at last come home. Henri suffered a heart attack in 1996 and was buried close to his beloved Daybreak community. His legacy lives on in the work of the Henri Nouwen Society, the Henri Nouwen Trust, the Henri J. M. Nouwen Archives and Research Collection, and in the enduring values of compassion, community and ministry that shine through all his writings.

NOTES

NOTES

NOTES

NOTES

Marjorie Thompson's authoring of Courage for Caregivers is a unique and rich contribution to the "vocation," of caregiving, which Marjorie knows both as freely chosen and as accepted in loving duty.

Schooled by Henri Nouwen at Yale, and by her mother and her mother-in-law through years of caregiving, Marjorie allowed her teachers to gift her with inner transformation on the journey toward deep integrity and compassion. This transformation is evident in the wide-ranging vision of caregiving offered here. Added to her personal growth and insights are the gifts and challenges of others in caregiving situations, along the spiritual perceptions of a lifelong pastor and friend to the suffering, Henri Nouwen. Marjorie Thompson has profound gifts for feeling, discerning, and writing.

SUE MOSTELLER, C.S.J.

*LITERARY EXECUTRIX AND TRUSTEE FOR HENRI NOUWEN LEGACY
TORONTO, ONTARIO*

What a precious resource Courage for Caregivers will be for those who give care and compassion. As a family therapist for over 40 years, I have had many occasions to share the works of Henri Nouwen with clients and to see their hearts and minds lifted with hope and strength at times of great pain and distress, and at times of deep joy and fulfillment in the journey of loving another. The guided process for a caregivers retreat is a brilliant and extremely helpful appendix to this beautifully written and illustrated guide for those called to being with, and walking alongside, others.

DIANE MARSHALL, RP, RMFT, REGISTERED PSYCHOTHERAPIST
THE INSTITUTE OF FAMILY LIVING, TORONTO

As someone who supports caregivers—those caring for loved ones and those involved in caring professions—I am excited for the opportunity to use this wonderful resource. Courage for Caregivers explores so many of the themes and questions people experience in a caring role. Henri Nouwen's words are treasured gifts that continue to inspire and strengthen, and the stories and reflective format will be invaluable to anyone looking for support in their caregiving roles.

MICHELLE O'ROURKE, RN, PALLIATIVE CARE NURSE AND EDUCATOR
AUTHOR OF BEFRIENDING DEATH: HENRI NOUWEN AND A SPIRITUALITY OF DYING

The relationship journeys of caregivers and care receivers are ones we may not or cannot anticipate or plan. We find ourselves in the land of vulnerability and weakness with a need to reorient. One pathway through the unfamiliar is the shared experiences and wisdom of others. Courage for Caregivers does just that. This resource opens up a space for exploration, acceptance, and understanding to find those places of hope, rest, and rediscovery. Through the lens of Henri Nouwen's wisdom, Marjorie J. Thompson shares her own personal journey and draws on the stories of others to reveal both the challenges and the unexpected blessings of hope.

DR. NEIL CUDNEY, DMIN, MTS

*DIRECTOR, ORGANIZATIONAL AND SPIRITUAL LIFE, CHRISTIAN HORIZONS
CO-CHAIR, ONTARIO FAITH AND CULTURE INCLUSION NETWORK
PRESIDENT, DIVISION OF RELIGION AND SPIRITUALITY,
AMERICAN ASSOCIATION INTELLECTUAL AND DEVELOPMENTAL DISABILITIES*