

CARE AND PRAYER

Reflections
on the Sacred Task
of Caregiving

GUNILLA NORRIS



TWENTY-THIRD
PUBLICATIONS

twentythirdpublications.com

TABLE OF CONTENTS

Note to the Reader	1	Just Us Here Now	46
Introduction	3	The Help of Others	49
Notes on Prayer	7	Love's Hands and Feet	51
<hr style="border: 1px solid black;"/>		The Art of Living	54
Invited into Life	13	Suffering Side by Side	56
The Gaze of Love	15	With-dom	59
The Inner <i>Yés</i>	17	Claiming Our Intentions	61
Becoming Real	19	Ordering Our Days	64
Egg on Our Faces	22	Refuge	66
Knowing We Don't Know	24	Off the Books	69
It Is What It is	27	Joy Training	72
Tumbled to the Shore	29	Tender Questions	74
Those Kin to Us	32	Stark and True	77
Treading Water	34	Sleeves Rolled Up	80
Mutual Compassion	37	When Character Is Fate	82
On Different Rails	39	Patience	85
The Boomerang of Love	41	<hr style="border: 1px solid black;"/>	
The Right to <i>Be</i>	44	A Last Word	88

I N T R O D U C T I O N

A book is not alive without its readers. Thank you for making this book come alive in some way that I will never know. For me that is a good mystery, and one I will never want to solve.

As a writer the inspiration for a book happens in many ways. Perhaps a powerful image or experience prompts the writing. Sometimes a need to address something important or difficult arises. Mostly ideas come and then leave—out of the mind and out the door. But some stick to you and demand to be taken seriously.

I was so through with caregiving. I never wanted to think about it ever again. I was a caregiver to my beloved partner, Stanley, for over ten years. He had Parkinson's disease. His body failed him little by little. His mind filled with dreadful hell states and a fierce distrust and anger toward the very person who was giving her all to him day after day. This, I later learned, is a very common symptom of Parkinson's disease. We know caregiving is not for sissies. We have to be present to what comes. It's like riding an escalator. We are moved relentlessly. Even though there may be plateaus, they don't last, for the escalator keeps going, and all we can do is to be fully on the step we are

on and do, there, the best we can while we are moved from one level to the next.

I don't want to go into the details of what happened to me.* Instead, I trust that I never write a book alone. Circumstances, lived experiences, chance, conversations, wounds, and hopes are all there as inspirations— a crowd helping the process along. I have learned to be a willing servant to what wants to happen. Besides, a teasing angel at my shoulder was very irritating, and to comply with her insistence I had to write.

Then there is also *you*, the reader, to whom this book is addressed. I am reaching out to you in these reflections. The squiggles on a page amount to nothing without your eyes, your heart, your understanding, experience, and participation.

You will soon find out that this book is not a *how-to* book. I don't know enough to write such a book. There are hundreds of them dealing with memory loss, cancer, help for those who suffer from immune diseases, and so on. There are also books giving expert advice for caregivers on how to take care of themselves. What criteria, then, do I have to write about caregiving? Only this: I loved and suffered with my partner for ten years, coping with the relentless decline of Parkinson's disease. I was not a great caregiver. I made lots of mistakes, but I showed up, and I could not have done so without a prayer life. It is what sustained me.

As you read this book please also sense and join the vast numbers of people, past, present, and future, who are giving

*You can read about that in my two books of poetry: *Joy Is the Thinnest Layer* and *Calling the Creatures*.

or have given care. We are not alone in our journeys. We are part of the family of humanity, where helping one another is central to being human. It shapes who we become.

The giving of care is fraught with many things: love, responsibility, relentlessness, confusion, control, fatigue, anger, despair, humor, sadness, and God's presence throughout it all, if we would only sense it, and find that, as we love, we are also being loved.

Not everything on these pages will be relevant to you. May you be sustained as you live this holy task of giving care. Skip those parts that don't speak to you. Opening the book at random might work for you. The reflections are short on purpose. Caregivers have so little time! The prayers are even shorter, though one or two might reach into a place where Spirit can enter and be with you. They will then turn out to be long in both forming and transforming your heart. May you be supported and find tender, respectful ways to live, not just for the one you are caring for but for yourself as well.

I do not for a minute take you or your reading of this book for granted. It is you who will make this book come alive just as the ears of people at a concert make music felt and heard.



Invited into Life

We suffer a lot when the one or ones we care about are suffering. We also ache when our own emotional and physical challenges overwhelm us. It is very hard then to remember that God loves us. Those words become only words, even platitudes.

The truth is that the Old English meaning of the word *suffer* was *to allow*. When too much pain fills our lives and the lives of others, we can't feel that God's love is present. Our doors to love slam shut. We wonder where God is as we suffer.

It may seem impossible to understand that God's love is not a love that prevents suffering, but a love that joins in the unfolding of whatever is occurring. God suffers and rejoices in every one of us. God participates. There is no old, white Patriarch in the sky who points at us with a condemning finger. Instead, there is unlimited life, and the freedom to be in its unfolding. God's love is an allowing love. It asks us to take up our lives and unfold them with as much human care as we can muster. It is there, in the living, that meaning is to be found.

To love life is to accept that it cannot be controlled. It can only be lived. Allowing God's gift of possibility is to

remember we are not facing what we face alone. As close as our next breath, God invites us into Life—the very one we are living now. Can we remember that immense gift as we suffer? To *remember* is to connect again, to become once more a *member* of Life itself just as it is and to God who can never be defined, but whom we can sense being near to us and suffering with us. We start there. We live there every moment. God never abandons what God created. We need daily to remember the truth of that.

*When I falter and distrust,
when I ache and suffer
beyond what I think I can take, let me know
that here, in this frail human body
I am yet a member of Your body,
Your creation.*

*Let my mind be still
and the truth of your Presence be
what I come to know in my very cells.*

*May I not ask, “Why me?”
Instead may I be led to the tasks
that are truly mine to do.
May I remember Your love
and say, “Yes.”*



The Gaze of Love

In the tension, the slop, and the cleanup, the hurry and waiting, fearing and unknowing that fill a caregiving day, how can we possibly grasp that we are revered and precious? *Who me?* we might ask, sleeves pulled up, half-eaten sandwich on the table, dishes in the sink.

But if we could peer behind and under the veil of appearances, we might sense that infinite love is pouring into us and into what is all around us. Yes, that is a leap of faith, and that leap cannot happen without profound humility. It is the willingness to give up the veil of comfy, controlling self-assessments of how nice we are as well as the automatic, negative judgments about our selves and our situations.

Being willing to see behind the veil takes enormous guts. To let go of being right about our unworthiness or our self-serving goodness and how unfair life can seem to be: this will only happen in humility. To dare to believe that we are loved beyond anything that seems to prove otherwise is to be ego-reduced. It is an abject state in which we are not able to claim anything. And yet it is precisely there that God honors us. God loves our weakness and our need. That undeserved love is what can fuel us for the tasks at hand.

To claim and to be in this fundamental state of humili-

ty is perhaps the only way we can stay whole in the grief, hopelessness, and exhaustion that caregiving can become. We need practice. Before a mirror in our homes let us look into our own eyes. Can we simply look and not assess? Can the eyes that we see with just gaze at the one who stands there? Perhaps we can learn to baby-gaze. Infants and toddlers just look and experience, don't they? They have no pre-judgment. With curiosity and interest, they are taking in what is present. It is a kind of sacred gazing. If we can learn to do this as conscious adults we would be a step closer to knowing that we are already known in our strengths, our frailties, our faults, and our preciousness. There's nothing to hide and everything to gain. Can we let ourselves be naked and love-seen by God? Can we let ourselves be held dear?

*How can I rid myself of the veils
with which I cover myself;
not being enough, not caring
as much as I think I should?*

*I dress myself in my oh so familiar
rain and storm gear—those negative opinions
of who I believe myself to be.*

*Sometimes I brag inside when no one can see it.
Look how good I am
as I demonstrate my care.*

*Secretly I want to believe
there is only this wonderful me
proving myself to everyone.*

*Your presence wants me naked to Your love.
Teach me humility. Help me give up
the sweet control
I find in self-assessment.
Help me unbutton and unzip.*



The Inner *Yes*

The daily gift of being remembered into God's keeping and growing the humility of letting in, little by little, how much we are cherished and revered can change the course of our caregiving from one of dread and obligation to one of courage and acceptance.

It helps a great deal to acknowledge that caregiving is not bondage, but a holy task, one of service and dignity. It's true that caregivers are often taken for granted, left in the lurch with the whole catastrophe. They are often not thanked, and most likely they will be criticized for the ways they are handling things. Who would want such a job unless they were called to it?

Understood as a holy task, the job shows up with our

names on it. We can't avoid what belongs to us. It arrives on the doorstep in one way or another. Having refused it previously, it will nevertheless appear again as part of our path in life. Looking back, years later we might smile ruefully and see how much we squirmed and avoided what was a central truth of our lives.

The entire enterprise shifts when we see, think, feel, and surrender to our inner *yes*, our acceptance of the caregiving path before us. It will test us to the core, and the test will shape us into more of who we really are.

Recognition of this kind is a mystery. We can't argue with it, though we might try. It feels horrible, tremendous, scary, and yet so *right* in some unfathomable way. We can only proceed in the task by knowing that we have been in some way loved into it—remembered, revered, and recognized. It can then become for us holy work.

We don't really know what we have signed up for, do we? Somehow it just happened. Then every day is a school day in learning what care is. We also find out what care is not. Ever so slowly we become simplified, and re-created around caring. A new center emerges unbeknownst to us. We become part of the Mystery that is love.

*I know this is mine to do.
I often wish that it were otherwise.
Your love has put me here.*

*If I avoid it,
I diminish myself.*

*If I take it on,
I must trust
that You will walk with me.*

*I wobble. I teeter.
But the truth is
that You have recognized me and therefore
I can recognize this love-task as mine.*

*I need Your help. Be by my side
Help me grow into the love
You trust me with.*



Becoming Real

When the caregiving task is felt and known to belong to us, we take on the responsibility of it. It happens almost despite us. At the core an inner response, an inherent ability to respond, takes up the challenge that we will never know the full dimensions of. It's like finding oneself in midair before plunging into deep waters and beginning to swim.

Caregiving that arises through obligation, arm-twisting, or people pleasing is not true caregiving. It's a way to assuage doubt and to keep other people's expectations and

criticisms from overwhelming us. There are many ego-based reasons to do what we are *not* called to do.

Under those auspices we will not have the deep resources of true response-ability. The caregiving that truly belongs to us is not only necessary for the person we are caring for, but also for us as well. It will make us whole in an inexplicable way.

All kinds of caregiving may look the same on the surface. Caregiving, as a profession for which one is paid, can be heartfelt. It may not seem on a par with voluntary caregiving in a family or for a friend, but at the core it is the quality of care that matters. Those who are getting the care can feel the difference. In one they are objectified. They are treated like a job to be done and gotten through. In the other they can sense themselves as persons who are valued. Person to person, response to response, such caregiving can feel like a gift from heaven. Even in the midst of pain, fatigue, and the seeming endlessness of the task, the gift of responding shines and sheds a light between giver and receiver.

Looking at response a little more deeply, we can see that it hinges on being present in the moment. Present, moment-to-moment, our lives become momentous. To live this way is to live a deep human capacity, one that requires something simple and very hard—willingness to pay attention beyond our own concerns. We have to be present to respond. Maybe we could say that it is only when we are present that we truly are persons. The rest of the time we are on an automatic program simply functioning and not really alive. We are in a kind of limbo.

The difference one feels when someone is truly present to us is a profound difference. It is a gift in which we are mutually made real.

*How sad it is when I discover
how often the only world that matters to me
is the one I manufacture.*

*You are always here, and I am so often not here.
I see how much of my concerns are about me
and mine, and they distance me from Your love.*

*Bring me back.
Bring me into personhood again,
into deep response to You
and to others whom You love
and who are meant for me to love.*

*Let me not live an automatic life.
Help me to be present,
to use my heart and hands
in conscious care.*