THE OTHER PATIENT

There Are Two Lives in Every Caregiving Story

The Presence Network

Final Manuscript • Introduction, Chapters 1–11, Afterword & Caregiver Promise

Introduction

The Person Beside the Bed

There is someone we often overlook.

You can find them sitting beside a hospital bed.

Sleeping in a recliner in a living room.

Standing at the kitchen counter sorting medications into little plastic containers.

Waiting in the car outside a doctor's office.

Helping someone into the shower.

Changing sheets in the middle of the night.

Listening for breathing from the next room.

Watching the clock.

Waiting for the next dose.

Waiting for the next appointment.

Waiting for the next change.

Waiting for the phone to ring.

They are not the patient.

At least, that's what everyone says.

They are the caregiver.

And sometimes they are slowly becoming the other patient.

Not because they are weak.

Not because they are incapable.

Not because they don't understand the importance of taking care of themselves.

Sometimes it happens for a much more beautiful—and dangerous—reason.

They love someone.

When someone you love becomes seriously ill, priorities change almost overnight.

Things that once seemed important suddenly aren't.

The calendar changes.

The household changes.

Conversations change.

Finances change.

Sleep changes.

Relationships change.

Even the way you listen changes.

You begin listening differently.

Was that cough different?

Did he take his medicine?

Did she eat enough?

Why is he sleeping so much?

Was her breathing like that yesterday?

Should I call the doctor?

Should I call hospice?

Should I wake her?

Should I let him sleep?

Is this normal?

Is something happening?

You become a watcher.

A listener.

A protector.

And sometimes without realizing it, you become the person standing between someone you love and everything you're afraid might happen to them.

That's an enormous responsibility for one human being to carry.

But caregivers carry it every day.

"I'll Take Care of Me Later"

There is a sentence caregivers don't necessarily say aloud.

But many live by it.

I'll take care of me later.

My appointment can wait.

My back will be okay.

I'll sleep tomorrow.

I'll eat after she eats.

I'll refill my prescription next week.

I'll reschedule the mammogram.

I'll get my blood pressure checked eventually.

I'll call my doctor when things settle down.

I'll see my friends another time.

I'll take a break when someone else can stay with him.

I'll deal with how I'm feeling after we get through this.

Later.

Later.

Later.

The problem is that caregiving doesn't always provide a later.

One crisis becomes another.

One appointment becomes three.

A temporary decline becomes a new normal.

Weeks become months.

Months become years.

And somewhere during all that loving, watching, protecting and caring, the caregiver begins disappearing from their own life.

Not Neglect. Love.

We need to be careful with the language we use here.

It is easy to say that caregivers "neglect themselves."

Sometimes they do.

But that description can sound accusatory.

As though they have done something irresponsible.

Often something much more complicated is happening.

Imagine your spouse of fifty years needs help getting out of bed tomorrow morning, and your own routine doctor's appointment is scheduled at the same time.

Which one feels urgent?

Imagine your mother becomes confused whenever you're away, but you desperately need an afternoon to yourself.

Which need wins?

Imagine your husband is declining and you don't know how many good days remain.

Are you really going to leave for several hours because somebody told you that you should practice "self-care"?

These aren't easy decisions.

Love complicates them.

Fear complicates them.

Guilt complicates them.

And sometimes caregivers make the same decision over and over again:

You first.

I'll be okay.

And that can be an extraordinarily beautiful expression of love.

Until "you first" quietly becomes:

me never.

That's where we need to pay attention.

CHAPTER ONE

There Are Two Lives in This Room

Walk into almost any room where someone is seriously ill and your eyes naturally move toward the person in the bed.

Of course they do.

They are the patient.

We ask about their pain.

Their breathing.

Their medications.

Their appetite.

Their sleep.

Their symptoms.

Their comfort.

Their prognosis.

We measure.

We document.

We observe.

We treat.

And sitting three feet away may be another person whose body is telling an entirely different story.

They haven't slept through the night in weeks.

Their blood pressure has been climbing.

Their back hurts from helping someone transfer from the bed.

They've been living on coffee and whatever food happens to be nearby.

They haven't taken their own medication yet today.

Their doctor's office has called twice trying to reschedule an appointment they canceled.

They haven't seen their friends.

They haven't been to church.

They haven't exercised.

They haven't laughed much lately.

And when someone asks:

"How are you doing?"

They give the answer caregivers have perfected.

"I'm fine."

Then they immediately redirect the conversation.

"But I'm worried about him."

And everyone's attention returns to the bed.

Exactly where the caregiver wanted it.

The Invisible Patient

Caregivers become remarkably good at disappearing.

They don't mean to.

It happens gradually.

At first, they are simply helping.

Driving to appointments.

Picking up prescriptions.

Making a few meals.

Checking in.

Then something changes.

A fall.

A hospitalization.

A diagnosis.

A progression of disease.

A cognitive decline.

A terminal prognosis.

And "helping" becomes something entirely different.

Now somebody needs supervision.

Someone needs help bathing.

Someone needs assistance getting to the bathroom.

Someone can't safely be left alone.

Someone wakes throughout the night.

Someone needs medications at particular times.

The caregiver's life begins reorganizing itself around another person's needs.

And because those needs are real, the caregiver's needs begin feeling optional.

That distinction matters.

Their needs are urgent.

Mine can wait.

Their pain matters.

Mine isn't that bad.

Their appointment matters.

I'll reschedule mine.

They need sleep.

I'll stay awake.

They need nutrition.

I'll grab something later.

They need somebody.

I'll stay.

Day after day, the caregiver moves farther down their own priority list.

Until sometimes they disappear from it altogether.

"But I'm Not the Patient"

That sentence reveals something important.

Caregivers don't necessarily see themselves as someone deserving care in this moment.

Care belongs to the sick person.

The caregiver provides it.

Those roles become deeply established:

You receive.

I give.

But human beings weren't designed to live indefinitely in only one direction.

Everyone who gives eventually needs to receive.

Everyone who holds eventually needs to be held.

Everyone who listens eventually needs someone to listen to them.

Everyone who carries eventually needs somewhere to put the weight down.

That isn't weakness.

That's being human.

And yet many caregivers struggle enormously with receiving.

Someone says:

"Can I bring dinner?"

"No, we're okay."

"Can I stay with her while you get out?"

"No, I don't want to bother you."

"Do you need anything?"

"We're fine."

"How are you doing?"

"I'm okay."

Sometimes "I'm okay" really means:

I don't have enough energy to explain how not okay I am.

The Body Doesn't Know You're Being Noble

There is something caregivers need to understand.

Your body doesn't know why you're under stress.

It doesn't know that you stayed awake because you love your husband.

It doesn't know that you skipped lunch because your mother needed you.

It doesn't know that you canceled your doctor's appointment because your wife couldn't safely be left alone.

It only knows what is happening inside you.

Not enough sleep.

Interrupted rest.

Constant vigilance.

Muscle tension.

Irregular meals.

Fear.

Uncertainty.

Grief.

Adrenaline.

Stress.

Again.

And again.

And again.

Love may explain why you're carrying the load.

But love doesn't make your body immune to the weight.

That may be one of the most important truths in this book:

A loving sacrifice can still cost you something.

Acknowledging the cost doesn't diminish the love.

It honors reality.

Caregiving Often Begins Before Grief Has a Name

There is something else happening in many caregiving homes.

Grief has already arrived.

Nobody has died.

But something has already been lost.

The marriage may have changed.

The person who once shared household responsibilities may now depend upon you.

The mother who once cared for you may now need you to care for her.

The person you used to travel with may no longer be able to leave the house.

Conversations may have changed.

Intimacy may have changed.

Plans may have changed.

The future you imagined together may be disappearing.

This is sometimes called anticipatory grief.

But caregivers don't always have language for it.

They simply know:

I miss us.

And then they feel guilty for thinking it because the person they love is still sitting right there.

But grief isn't a betrayal.

You can be deeply grateful that someone is still here while simultaneously grieving what illness has taken.

Both can be true.

Love makes room for both.

Who Is Watching the Watcher?

Perhaps this is the question healthcare professionals, families, churches, hospices and communities need to begin asking:

Who is watching the person who is watching the patient?

Who notices that Dad looks exhausted?

Who asks Mom when she last saw her physician?

Who makes sure the daughter caring for both parents still has a life outside their home?

Who notices that the husband hasn't slept?

Who recognizes that the wife keeps saying she's fine while tears appear every time somebody asks how she's doing?

Who cares for the caregiver?

Sometimes the answer is:

Nobody.

Not because nobody loves them.

Because everyone is looking at the obvious patient.

This book is asking us to widen the frame.

Look at the bed.

Absolutely.

But then look beside it.

There is another person there.

Another heart.

Another nervous system.

Another body.

Another story.

Another future.

Another human being whose life matters.

If You Are the One Beside the Bed

Perhaps that person is you.

Maybe you're reading this while someone you love is sleeping.

Maybe you're sitting in a hospital waiting room.

Maybe you're exhausted.

Maybe you're scared.

Maybe you're doing things you never imagined you would have to do.

Maybe people keep telling you how strong you are.

And secretly you're tired of being strong.

Then hear this.

You don't have to become less devoted to the person you love.

This book isn't going to ask you to care less.

We are going to talk about something different.

How do we care for them without losing you?

How do we protect your health while honoring theirs?

How do we make room for your exhaustion without making you feel guilty?

How do we allow other people to help?

How do we recognize when love has quietly crossed the line into self-erasure?

And eventually, if caregiving ends in death, how do we care for the person who remains when the person they organized their life around is suddenly gone?

Those are the questions ahead.

But for now, we begin with one.

Look around the room again.

There is the person you love.

And there is you.

There are two lives in this caregiving story.

And both are worthy of care.

A Presence Moment

Before moving to the next chapter, don't make a list.

Don't promise yourself you'll exercise more.

Don't create another assignment.

Just sit quietly for a moment and ask:

When was the last time I allowed someone to care for me?

Don't judge the answer.

Just notice it.

Because perhaps caring for the caregiver doesn't begin with doing something.

Perhaps it begins with finally seeing them.

And if you are the caregiver—

perhaps it begins with finally seeing yourself.

CHAPTER TWO

Because I Love You

There are three words behind much of what caregivers do.

Because I love you.

Why did you get up again at two o'clock in the morning?

Because I love you.

Why did you cancel your plans?

Because I love you.

Why haven't you taken a vacation in three years?

Because I love you.

Why did you learn how to manage medications, change dressings, operate equipment, prepare special meals, help someone bathe, or safely move a body that no longer moves the way it once did?

Because I love you.

Why are you sitting beside this bed when you're exhausted yourself?

Because I love you.

That answer deserves respect.

Caregiving is often one of the most intimate expressions of love one human being will ever offer another.

There may be no audience.

No applause.

No recognition.

Sometimes no thank-you.

Just two people in a quiet house and one saying to the other through a thousand ordinary acts:

I'm still here.

But there is something we need to talk about.

Because sometimes the very love that keeps us beside someone can make it difficult to recognize what is happening to us.

Love Doesn't Keep Score

Most long-term relationships are built on thousands of exchanges we never record.

You cooked.

I cleaned.

You drove.

I made the appointment.

You remembered the birthday.

I picked up the groceries.

You stayed awake with the baby.

I got up early.

You carried me through that difficult year.

I carried you through another.

We don't usually keep a ledger.

That's part of love.

But serious illness can dramatically change that balance.

The person who once cared for you may no longer be able to.

The spouse who once shared the household responsibilities may now require help completing the simplest tasks.

The parent who once protected you may now depend upon you for protection.

The relationship hasn't necessarily become less loving.

But it has become less reciprocal.

One person increasingly receives.

The other increasingly gives.

And gives.

And gives.

At first, that may not feel burdensome at all.

You simply do what needs to be done.

But eventually something happens that caregivers rarely talk about.

You become tired of giving.

And then you feel terrible for being tired.

"I Shouldn't Feel This Way"

Caregivers have feelings they sometimes don't want anyone to know about.

Frustration.

Anger.

Resentment.

Impatience.

Loneliness.

Jealousy of people whose lives seem normal.

Relief when someone else takes over.

The desire to get away.

The wish that this would all be over.

And sometimes immediately after having one of those thoughts comes another:

What kind of person thinks that?

A tired one.

A frightened one.

A grieving one.

A human one.

Having a difficult thought does not mean you don't love the person you're caring for.

Feeling frustrated doesn't erase decades of devotion.

Wanting an afternoon away doesn't mean you're abandoning anyone.

Being exhausted by caregiving doesn't mean you're exhausted by the person.

Those are different things.

You can love someone completely and still be overwhelmed by what their illness requires of you.

Both can be true.

The Guilt Hidden Inside Love

Guilt is one of caregiving's quietest companions.

It whispers.

You should be doing more.

You shouldn't be tired.

Don't complain. They're the one who's sick.

What if something happens while you're gone?

What if this is one of their last good days?

You promised you would always be there.

So you stay.

And sometimes staying is exactly where you want to be.

But sometimes guilt begins making decisions that love never asked it to make.

There is a difference between:

I want to stay with you.

and

I'm afraid to leave you.

There is a difference between:

I choose to care for you.

and

I believe I'm a bad person if I let anyone else care for you.

There is a difference between devotion and disappearance.

Those differences aren't always easy to recognize when you're living inside them.

"Nobody Knows Them Like I Do"

And perhaps nobody does.

You know the way she likes her pillows arranged.

You know which cup he prefers.

You know the look that means she's hurting even when she says she isn't.

You know when his breathing sounds different.

You know which foods she will eat when nothing sounds good.

You know how to calm him when he becomes frightened.

You know the routines.

The history.

The preferences.

The personality.

You know the person beneath the diagnosis.

That knowledge is precious.

It is also one reason caregivers sometimes become trapped.

Because if nobody knows them like you do, then nobody can replace you.

And if nobody can replace you, then you can never leave.

Not for an afternoon.

Not for an appointment.

Not for dinner.

Not for rest.

Not even when you're sick yourself.

But perhaps we have confused two different things.

Someone else doesn't have to replace you in order to relieve you.

They don't have to love your spouse exactly as you do.

They don't have to know your mother exactly as you do.

They don't have to become you.

They only need to become trustworthy enough for you to step away for a little while.

Help doesn't diminish your place.

It protects it.

The Promise We Never Actually Made

Many caregivers live under an invisible promise.

I will never leave you alone in this.

It's a beautiful promise.

But over time it can quietly become something else:

I will do everything myself.

Those are not the same promise.

You can remain faithful without doing everything.

You can remain present while allowing other people to participate.

You can love deeply and still sleep.

You can be devoted and still see your doctor.

You can keep your promise and still take an afternoon away.

You can sit beside someone faithfully without sitting there every minute.

Presence is not measured by exhaustion.

Love is not proven by collapse.

When Sacrifice Becomes Identity

There can also be something strangely meaningful about being needed.

Someone depends upon you.

Your presence matters.

Your decisions matter.

Your hands matter.

You are protecting someone you love.

That creates purpose.

And purpose can carry us through extraordinarily difficult seasons.

But over time, something subtle can happen.

You stop saying:

I care for my husband.

And somewhere inside yourself it becomes:

I am his caregiver.

You stop saying:

I'm helping Mom.

And it becomes:

Mom can't manage without me.

The role begins absorbing the person.

Other parts of your identity grow quieter.

Friend.

Spouse.

Parent.

Grandparent.

Neighbor.

Artist.

Gardener.

Traveler.

Reader.

Musician.

Person who laughs.

Person who dreams.

Person who has needs.

Person who has a future.

Caregiving may be something you are doing with extraordinary love.

But it is not the entirety of who you are.

You existed before this role.

There is still a person underneath it.

And that person matters.

Love Shouldn't Require Your Disappearance

There is a particular kind of love that says:

I would give my life for you.

Many caregivers understand that sentence.

They mean it.

But most caregiving doesn't ask for one dramatic act of sacrifice.

It asks for thousands of small ones.

An hour of sleep.

A canceled lunch.

A missed appointment.

A weekend away.

A friendship.

A hobby.

A walk.

A meal.

A moment alone.

None seems catastrophic.

That's why the danger can be difficult to see.

You rarely disappear all at once.

You disappear a little at a time.

Until one day someone asks:

"What do you enjoy doing?"

And you can't remember.

Or:

"When was the last time you did something just for yourself?"

And you have to think about it.

Or:

"How are you feeling?"

And you realize you haven't asked yourself that question in months.

This is not a criticism.

It's an invitation to notice.

Caring For You Is Part of Caring for Them

Perhaps we need a different understanding of self-care.

Not:

I need to take care of myself instead of taking care of you.

But:

Caring for myself is part of how we are going to get through this together.

That changes things.

Your doctor's appointment isn't competing with theirs.

Both matter.

Your sleep isn't taking something away from them.

It helps sustain the person they depend upon.

Your friendship isn't an indulgence.

It reminds you that you still belong to a world larger than illness.

Your laughter isn't disrespectful.

Your joy doesn't betray their suffering.

Your moments of peace don't mean you've forgotten what they're going through.

And accepting help doesn't mean you failed.

It means you finally allowed caregiving to become something larger than one exhausted person trying to hold everything together.

The Person You Love May Need This Too

There is another possibility worth considering.

What if the person you're caring for doesn't want you to disappear either?

Imagine asking them:

"Would you want me to become sick caring for you?"

Most would say no.

Would they want you to stop seeing your doctor?

Probably not.

Would they want you to lose every friendship?

No.

Would they want your world to become so small that nothing remains except illness?

No.

Would they want you to survive them but have no idea how to live afterward?

Probably not.

Sometimes caregivers sacrifice things their loved one never asked them to sacrifice.

Love can become so protective that we stop asking what love actually requires.

Perhaps the person lying in the bed would say:

Go.

Have lunch.

See your doctor.

Take the walk.

Sleep tonight.

Let someone else sit with me.

I'll be okay.

And perhaps one of the hardest acts of love is believing them.

"But What If Something Happens?"

This is where the fear becomes real.

Because something could happen.

Caregivers know that.

A fall could happen while you're gone.

Breathing could change.

A crisis could occur.

The phone could ring.

The person could decline.

And yes, someone could die while you aren't in the room.

That possibility carries enormous emotional weight.

It can make a caregiver afraid to leave at all.

But no human being can control every moment of another person's life.

Caregiving can create the illusion that if we remain vigilant enough, careful enough, attentive enough and present enough, we can prevent every bad thing from happening.

We can't.

That isn't failure.

It's mortality.

You can be faithful without being omnipresent.

You can love someone without controlling every outcome.

You can leave the room and still love the person inside it.

Because I Love You — And Because I Matter Too

Perhaps we don't need to abandon those three words.

Because I love you.

Maybe we simply need to expand them.

Because I love you, I'll sit beside you.

Because I love you, I'll learn what you need.

Because I love you, I'll hold your hand when you're frightened.

Because I love you, I'll advocate for your comfort.

Because I love you, I'll stay when staying matters.

But also:

Because I love you, I'll let someone help us.

Because I love you, I'll try to sleep.

Because I love you, I'll keep my medical appointments.

Because I love you, I'll tell someone when I'm overwhelmed.

Because I love you, I'll protect enough of myself to continue loving you without disappearing.

And perhaps eventually:

Because I love you, I will remember that my life matters too.

Not more than yours.

Not instead of yours.

Alongside yours.

There are still two lives in this room.

A Presence Moment

Don't change anything yet.

Don't make a self-care plan.

Don't promise to do better.

Just become quiet for a moment.

Think about something you have stopped doing since becoming a caregiver.

Something small.

Maybe something you loved.

Maybe someone you enjoyed.

Maybe somewhere you used to go.

Maybe an appointment you've postponed.

Maybe sleep.

Maybe laughter.

Maybe simply sitting somewhere without listening for someone to call your name.

Now ask yourself one question:

Did the person I love actually ask me to give this up?

Sit with that question.

No guilt.

No judgment.

Just notice what comes.

And perhaps allow another question to follow:

What would love look like if both of our lives mattered?

Because they do.

There are two lives in this caregiving story.

And you are one of them.

CHAPTER THREE

I'll Take Care of Me Later

There is always something more urgent.

That's one of the difficulties of caregiving.

Your loved one's needs arrive with a clock attached to them.

The medication needs to be given now.

The appointment is today.

The meal needs to be prepared.

The bathroom can't wait.

The phone call from the doctor's office needs to be answered.

The prescription needs to be picked up.

The pain needs attention.

The breathing needs to be watched.

Your needs rarely announce themselves with the same urgency.

Your blood pressure doesn't necessarily hurt.

Exhaustion doesn't always feel like an emergency.

The appointment you cancel can usually be rescheduled.

The prescription you forgot can be picked up tomorrow.

The screening you've postponed probably doesn't seem important today.

The pain in your back?

You've had it for weeks.

The headache?

Probably stress.

The strange discomfort?

You'll keep an eye on it.

The fatigue?

Of course you're tired.

You're a caregiver.

And so, without making any conscious decision to neglect yourself, you begin living by a simple rule:

I'll take care of me later.

Later Feels Reasonable

That's what makes this so difficult.

Later doesn't sound irresponsible.

It sounds practical.

Your husband has an oncology appointment Tuesday morning.

Your annual physical is scheduled at the same time.

Which one gets moved?

Yours.

Your mother had a difficult night and finally fell asleep at six in the morning.

You were supposed to have blood work at eight.

You cancel it.

Your wife can't safely be left alone, and the person who normally stays with her isn't available.

You have a dental appointment.

You reschedule.

None of these decisions seems unreasonable.

In fact, most of them make perfect sense.

That's why self-neglect in caregiving rarely begins with a dramatic decision.

It happens through a hundred perfectly understandable ones.

Not today.

Maybe next week.

After this appointment.

After we get the test results.

After things settle down.

But serious illness doesn't always settle down.

Sometimes it simply changes shape.

And the caregiver keeps waiting for a quiet season that never arrives.

Your Body Doesn't Understand "Later"

Your calendar understands postponement.

Your body doesn't.

Blood pressure continues being blood pressure.

Diabetes continues being diabetes.

A suspicious symptom doesn't know that your spouse has an appointment this week.

Your joints don't understand that someone needs help transferring from the bed.

Your immune system doesn't know that you're too busy to rest.

Your heart doesn't understand that this is a bad time for you to become ill.

Your body simply keeps living through whatever you ask it to carry.

Day after day.

Night after night.

That doesn't mean every headache is dangerous.

It doesn't mean every ache requires an emergency room.

And it certainly doesn't mean caregivers should become frightened of their bodies.

It means something simpler:

You are still living in your body while you're caring for someone else's.

And your body still deserves your attention.

"I'm Just Tired"

There may be no sentence caregivers say more often.

"I'm just tired."

Sometimes that's exactly what it is.

You had a difficult night.

You didn't sleep.

You've been running all day.

Of course you're tired.

But chronic exhaustion can become so normal that caregivers stop recognizing it as information.

They adapt.

One cup of coffee becomes two.

Two becomes three.

Bedtime gets later.

Sleep gets interrupted.

You wake up listening.

You check the clock.

You check the person beside you.

You listen for breathing.

You get up to help with the bathroom.

You return to bed but don't really return to sleep.

Morning comes anyway.

And you begin again.

Eventually, you may forget what rested feels like.

That's worth noticing.

Not judging.

Not fearing.

Not feeling guilty about.

Just noticing.

Because exhaustion is not a character flaw.

It is your body communicating with you.

The Symptoms We Explain Away

Caregivers become excellent explainers.

My back hurts because I helped move him.

My stomach hurts because I've been eating terribly.

My headaches are from stress.

My heart is racing because I'm anxious.

I'm dizzy because I didn't eat breakfast.

I'm short of breath because I'm out of shape.

I'm irritable because I haven't slept.

I'm forgetting things because I have too much on my mind.

Maybe.

Sometimes those explanations are exactly right.

But sometimes we use caregiving to explain symptoms that deserve attention.

There is an important difference between understanding why something might be happening and knowing why it is happening.

Caregivers don't need to become afraid of every sensation.

But neither should caregiving become the explanation for everything.

Some things deserve a phone call.

Some things deserve an appointment.

Some things shouldn't wait.

And urgent or severe symptoms should receive urgent medical attention.

The person you love is not the only person whose symptoms matter.

The Appointment You Keep Canceling

Think about your own healthcare for a moment.

Is there something you've postponed?

A physical?

A mammogram?

A colon cancer screening?

A dental visit?

Blood work?

An eye examination?

A follow-up appointment?

A prescription refill?

Something your physician asked you to return for?

Maybe the office has called.

Maybe you've looked at the number and thought:

I can't deal with that today.

That's understandable.

Caregiving can make even simple appointments feel impossible.

Someone has to stay with your loved one.

Transportation has to be arranged.

You don't know how long you'll be gone.

You worry something will happen.

And sometimes you're simply too exhausted to sit in one more waiting room.

But perhaps we can change how we think about that appointment.

It isn't time away from caregiving.

It is part of caregiving.

Because there are two lives in this story.

And keeping one alive should not require ignoring the other.

Food Becomes Fuel

Caregiving can change the way people eat.

You prepare the carefully balanced meal for the person you love.

Then you stand at the kitchen counter eating crackers.

You monitor their fluids.

Then realize at four o'clock that you've barely had anything to drink.

You make sure they receive the nutrition they need.

Then you grab whatever is easiest for yourself.

Sometimes food becomes less about nourishment and more about surviving the day.

There is no shame in that.

Some seasons are survival seasons.

But survival patterns can quietly become permanent patterns.

Your body still needs nourishment.

Not perfection.

Not an elaborate diet.

Not another program to follow.

Just care.

A glass of water.

Something nourishing within reach.

A meal somebody else prepared.

Accepting the groceries when someone offers.

Eating while the food is still warm.

Small things count.

The Medication Sitting Beside Theirs

There's something almost ironic about caregiving.

You may know exactly when your loved one's medications are due.

Eight o'clock.

Noon.

Four.

Bedtime.

You know which pill needs food.

Which medication causes sleepiness.

Which one can't be missed.

Which prescription needs refilling.

And then someone asks:

"Did you take yours?"

You pause.

You forgot.

Again.

Caregivers can become extraordinarily attentive to another person's medical needs while becoming increasingly inattentive to their own.

So perhaps your medication belongs on the caregiving schedule too.

Not as an afterthought.

Not if you remember.

Because your health is part of this household's health.

"I Can't Get Sick"

Many caregivers say this jokingly.

"I don't have time to get sick."

But beneath the joke is often real fear.

Because what happens if you do?

Who takes over?

Who knows the medications?

Who knows the routine?

Who knows how to calm them?

Who has the doctor's numbers?

Who knows what to do at three in the morning?

Sometimes caregivers don't merely neglect illness.

They almost refuse permission for illness to exist.

They push through.

They minimize.

They keep going.

Until the body makes the decision for them.

This is another reason accepting help before a crisis matters.

A backup plan isn't an admission that you're failing.

It's recognition that you're human.

Someone else should know where the medications are.

Someone else should know the phone numbers.

Someone else should understand enough of the routine to step in.

Not because you're planning to leave.

Because you are one person.

And one person should never be the entire emergency plan.

When Caring Becomes Carrying

Caregiving is physical.

We sometimes forget that.

Helping someone stand.

Moving someone in bed.

Assisting with bathing.

Helping with toileting.

Pushing a wheelchair.

Loading equipment.

Lifting oxygen equipment.

Changing bedding.

Reaching.

Bending.

Pulling.

Supporting.

Catching.

Sometimes the caregiver is smaller, older, or physically more fragile than the person they're helping.

Yet they keep doing it because someone has to.

Back pain becomes normal.

Shoulder pain becomes normal.

Bruises become normal.

Fatigue becomes normal.

But pain is information.

There may be safer ways to perform these tasks.

There may be equipment available.

There may be nurses, therapists, aides, hospice staff, family members, or others who can teach you how to move someone more safely.

Asking someone to show you isn't incompetence.

Nobody is born knowing how to safely transfer another human being.

You shouldn't have to learn everything through injury.

Sleep Is Not a Luxury

Perhaps nowhere is caregiver sacrifice more obvious than sleep.

Night changes everything.

The house becomes quiet.

Support disappears.

The phone stops ringing.

And the caregiver becomes the night watch.

Every sound matters.

Every movement wakes you.

Sometimes even silence wakes you.

You listen.

Are they breathing?

You get up.

You check.

You return to bed.

Then you listen again.

Even when nothing happens, your body may remain alert because something could happen.

That's not restorative sleep.

And after enough nights, exhaustion becomes part of your personality.

You may become irritable.

Forgetful.

Emotional.

Unfocused.

Clumsy.

You may begin wondering:

What's wrong with me?

Perhaps nothing is wrong with you.

Perhaps you're exhausted.

Sleep doesn't solve every problem.

But lack of sleep makes almost every burden heavier.

If nights have become unmanageable, tell someone.

Tell the nurse.

Tell the physician.

Tell hospice.

Tell your family.

Tell somebody.

Nighttime suffering shouldn't remain invisible simply because everyone else is asleep.

Your Healthcare Is Not Optional

Perhaps this sentence needs to be said plainly.

Being a caregiver does not cancel your status as a patient in your own healthcare.

You still deserve preventive care.

You still deserve treatment.

You still deserve sleep.

You still deserve nutrition.

You still deserve medical attention when something doesn't feel right.

You still deserve to ask questions about your own body.

You still deserve to say:

"I need help."

That isn't taking attention away from the person you love.

There is enough compassion for both of you.

Or at least there should be.

Don't Wait Until You're the Emergency

Sometimes families don't recognize caregiver exhaustion until the caregiver becomes ill.

Then suddenly everyone mobilizes.

Someone comes over.

Meals appear.

Schedules change.

Family members who couldn't find time before suddenly find it.

But why must the caregiver collapse before help becomes legitimate?

Why does exhaustion have to become illness before we take it seriously?

Why do we wait until someone says:

"I can't do this anymore"?

Perhaps we need to intervene earlier.

Not because the caregiver is incapable.

Because we want them to remain capable.

We shouldn't build caregiving plans that depend upon one person functioning indefinitely without interruption.

That's not a plan.

That's a countdown.

Maybe "Later" Can Be Today

This chapter isn't asking you to reorganize your entire life.

You probably don't have the energy for that.

And I don't want this book to become another person telling you everything you're doing wrong.

So let's make this very small.

Is there one thing you've been putting off?

One appointment?

One phone call?

One prescription?

One symptom you've been meaning to mention?

One person you've been meaning to ask for help?

One night when someone else might be able to stay?

One meal someone could bring?

One hour you could allow yourself to receive instead of give?

You don't have to fix everything.

Maybe you simply stop postponing one thing.

Because later has a way of moving.

Tomorrow becomes next week.

Next week becomes next month.

And eventually we can spend so much time waiting for life to become easier that we forget our own life is happening right now.

The person you love matters.

Their comfort matters.

Their health matters.

Their appointments matter.

Their medications matter.

Their body matters.

And so does yours.

There are two lives in this caregiving story.

Please don't make yours wait forever.

A Presence Moment

Become quiet for a moment.

Don't make a list.

Don't criticize yourself.

Don't think about everything you should have done differently.

Just ask yourself:

What have I been telling myself I'll take care of later?

Let the first answer come.

Maybe it's something physical.

Maybe emotional.

Maybe relational.

Maybe medical.

Maybe it's simply rest.

Now ask another question:

What would it look like to care for that one thing—not someday, but soon?

You don't need to solve it right now.

Just stop making yourself invisible.

Because somewhere along the way, while you were watching over someone you love, you may have forgotten something.

Someone is watching over a life that matters.

You.

And perhaps today is a good day to remember:

There are two lives in this room.

CHAPTER FOUR

Always Listening

There is a kind of listening that happens when you love someone whose health has become fragile.

It is different from ordinary listening.

You can be watching television and still hear the movement in the next room.

You can be washing dishes and notice that the coughing sounds different.

You can be having a conversation while part of your attention remains somewhere else.

You can be asleep and somehow hear the smallest change in breathing.

Caregivers learn this kind of listening without anyone teaching them.

You listen for footsteps.

For coughing.

For movement.

For silence.

Especially silence.

Sometimes silence is the loudest sound in the house.

You wake up.

You don't know why.

Then you realize.

You haven't heard anything.

So you listen.

Are they breathing?

You wait.

There it is.

A breath.

And only then do you allow yourself to close your eyes again.

This is caregiving too.

The part nobody sees.

The part that happens inside your body.

You are always listening.

The Watch Never Completely Ends

During the day, vigilance can look productive.

You check medications.

You watch for symptoms.

You notice changes.

You make appointments.

You ask questions.

You anticipate needs.

People may even praise you for it.

"You're so attentive."

"You notice everything."

"I don't know what we'd do without you."

And they're right.

Your attentiveness matters.

But the very ability that makes you an excellent caregiver can also become exhausting.

Because eventually your body may forget how to stop watching.

You sit down.

But you're still listening.

You leave the house.

But you're checking your phone.

Someone else stays with your loved one.

But you're wondering whether they remembered the medication.

You go to lunch.

But part of you is still at home.

Your body left.

Your attention didn't.

What If?

Caregiving creates a new vocabulary.

Two words appear repeatedly:

What if?

What if she falls?

What if he stops breathing?

What if the medication doesn't work?

What if the pain gets worse?

What if she tries to get out of bed?

What if he becomes confused?

What if I don't hear her?

What if something happens while I'm in the shower?

What if something happens while I'm at the store?

What if I fall asleep too deeply?

What if I make the wrong decision?

What if I miss something important?

What if tonight is the night?

These questions aren't irrational.

That's what makes them so powerful.

When you're caring for someone who is medically fragile, some of the things you're afraid of really could happen.

So your brain does what human brains are designed to do.

It tries to protect you.

It scans.

It anticipates.

It rehearses.

It prepares.

It watches.

Again.

And again.

And again.

The problem is that a system designed to protect us during danger was never meant to remain activated every hour of every day.

When Your Body Stands Guard

You may not think of caregiving as something happening in your nervous system.

But your body is participating in this experience right alongside your heart.

A sound occurs.

You become alert.

The phone rings.

Your stomach tightens.

Your loved one says, "I don't feel right."

Your entire body responds.

You walk into the room and immediately begin assessing.

How do they look?

How are they breathing?

Are they confused?

Are they in pain?

Do I need to call someone?

Your mind may be calm enough to handle the situation.

But your body has already received the message:

Something might be wrong.

That response can be useful.

It helps us act.

But when "something might be wrong" becomes the atmosphere in which you live, the body can have difficulty returning to rest.

The emergency may end.

The nervous system may not get the message.

Even Good Days Can Feel Dangerous

This is one of the strangest things about prolonged caregiving.

Sometimes you finally get a good day.

Your loved one eats.

The pain is controlled.

They laugh.

They seem more like themselves.

Nothing urgent is happening.

You should be able to relax.

But you can't.

Instead you think:

Why are they suddenly better?

Is this going to last?

What happens tonight?

Should I enjoy this, or should I be preparing for the next decline?

After enough unpredictable days, calm itself can begin to feel suspicious.

You don't trust it.

You wait for the other shoe to drop.

This doesn't mean you're pessimistic.

It means you've learned that things can change quickly.

Your body remembers that.

So even when the room becomes peaceful, part of you remains standing at the door.

Watching.

Waiting.

Listening.

The Phone Changes Meaning

Before caregiving, a ringing phone was just a ringing phone.

Now you look at the screen differently.

The doctor's office.

Hospice.

The hospital.

The pharmacy.

Your mother.

Your father.

The neighbor staying with your spouse.

A sibling calling at an unusual time.

Sometimes your heart responds before you've even answered.

The same thing can happen with text messages.

Or a sound from a medical device.

Or someone calling your name from another room.

Caregiving changes ordinary sounds into signals.

And after enough time, the body learns the association.

Sound means something may be needed.

So you remain available.

Even when you're exhausted.

Sleeping With One Ear Open

Caregiver sleep is often not simply shorter.

It can be different.

You may sleep lightly because you need to hear.

You may sleep in a chair.

On a couch.

Beside a hospital bed.

In another room with the door open.

You may wake every few hours for medications.

You may help with toileting.

You may reposition someone.

You may check oxygen.

You may respond to confusion.

Or perhaps nothing happens at all.

But you still wake.

Because you are listening.

This is why telling a caregiver to "get more sleep" can feel almost insulting.

They may desperately want to.

The question isn't always:

Why aren't you sleeping?

Sometimes the better question is:

What would have to happen for you to feel safe enough to sleep?

That's a very different question.

Maybe someone else needs to stay.

Maybe responsibilities need to be shared.

Maybe symptoms need better management.

Maybe the care team needs to know what nights actually look like in the home.

Maybe the caregiver simply needs permission to admit:

I can't keep doing nights by myself.

"I'm Fine When I'm Busy"

Many caregivers function remarkably well during a crisis.

There is something to do.

A problem to solve.

A phone call to make.

A medication to give.

A decision to make.

You become focused.

Competent.

Efficient.

Then the crisis ends.

The house gets quiet.

And suddenly you shake.

Or cry.

Or become irritable.

Or feel completely drained.

Sometimes people wonder why they fall apart after the difficult moment rather than during it.

Perhaps because during the crisis, your body helped you survive it.

Afterward, it finally asks you to feel what just happened.

There is nothing strange about that.

Strength during an emergency doesn't mean the emergency didn't affect you.

Sometimes the strongest people in the room are carrying the greatest physiological load.

The Fear of Missing Something

Caregivers often carry another burden:

responsibility for noticing.

What if I miss a symptom?

What if I give the medication too late?

What if I misunderstand what the nurse said?

What if I should have called sooner?

What if I don't recognize that they're declining?

What if they fall because I wasn't watching?

That can create an impossible standard.

You begin believing that enough vigilance can prevent every crisis.

But it can't.

You can pay attention.

You can learn.

You can prepare.

You can ask questions.

You can follow the care plan.

You can love extraordinarily well.

And something can still happen.

Illness is not completely controllable.

Neither is dying.

You are a caregiver. You are not a guarantee.

That distinction matters.

Because without it, every change can begin feeling like your responsibility.

And every outcome can begin feeling like your fault.

When Watching Becomes Your Whole World

Hyper-alertness doesn't always stay confined to caregiving tasks.

It can follow you everywhere.

You become more easily startled.

You have trouble concentrating.

You feel restless when you sit still.

You can't enjoy an outing because you're thinking about home.

You check your phone repeatedly.

You become irritated by small things.

Your mind feels foggy.

You forget why you walked into a room.

You lose things.

You cry more easily.

Or perhaps you discover you can't cry at all.

You may think:

I'm losing it.

But perhaps your mind has simply been asked to hold too much for too long.

Names.

Medications.

Appointments.

Symptoms.

Insurance.

Equipment.

Phone numbers.

Family concerns.

Medical information.

Household responsibilities.

Finances.

Work.

Fear.

Grief.

And somewhere inside all of that:

your own life.

That's a lot for one nervous system to carry.

You Need Somewhere You Don't Have to Watch

Caregivers need more than time away.

They need moments when they are not responsible.

There is a difference.

You can leave the house and still feel responsible.

You can go to dinner and check your phone twenty times.

You can lie down while listening for movement.

You can take a bath while wondering whether someone needs you.

That's technically a break.

But it may not feel like rest.

Real respite contains something else:

For this moment, someone else is watching.

Someone trustworthy.

Someone who knows enough.

Someone who can call if necessary.

Someone who allows your nervous system to hear a message it hasn't heard in a long time:

You are off duty for a little while.

That may be one of the greatest gifts anyone can give a caregiver.

Not simply:

"Go do something for yourself."

But:

"I've got this. You don't have to watch right now."

What Care Teams Need to Ask

When professionals enter the home, they naturally assess the patient.

Pain?

Breathing?

Appetite?

Bowels?

Medications?

Falls?

Sleep?

Those questions matter.

But perhaps there is another assessment that needs to happen.

Look at the caregiver.

And ask:

"How are nights going for you?"

Not the patient.

You.

How much are you sleeping?

Are you afraid to leave the room?

Do you feel comfortable leaving them with someone else?

When did you last get out of the house?

Are you constantly worried something will happen?

Is there anyone who can relieve you?

Do you know who to call when you're unsure?

Sometimes one compassionate question reveals an entire world nobody has noticed.

You Don't Have to Watch Every Second

This may be difficult to believe.

Especially if you've been doing this for a long time.

But you are allowed to stop watching sometimes.

Not because nothing could happen.

Something could.

But because no human being can remain vigilant indefinitely.

Your loved one needs care.

They do not need your nervous system destroyed in the process.

You are allowed to sleep.

You are allowed to leave the room.

You are allowed to turn your phone over during lunch while someone trustworthy is caring for them.

You are allowed to ask another person to listen for a while.

You are allowed to say:

"I need someone else to be responsible for the next few hours."

That isn't abandonment.

That's sustainability.

When Silence Becomes Safe Again

Perhaps someday the house will become quiet.

Not the frightening quiet you have learned to listen to.

Just quiet.

You may sit beside a window.

Drink coffee while it's still warm.

Take a shower without rushing.

Walk outside without carrying your phone in your hand.

Sleep without listening for movement.

At first, that kind of quiet may feel strange.

Your body may not trust it.

That's okay.

It has spent a long time protecting someone you love.

It may take time to learn that it no longer has to stand guard every moment.

And if you're still actively caregiving, perhaps you don't need to wait until the journey is over to experience a little of that quiet.

Maybe someone else can watch for an hour.

Maybe someone else can listen tonight.

Maybe you can step outside.

Maybe you can close your eyes.

Maybe, for just a few minutes, nothing is required of you.

A Presence Moment

Find a quiet place if you can.

You don't need complete silence.

Just a moment.

Notice your body.

Not what's wrong with it.

Just notice it.

Are your shoulders tight?

Is your jaw clenched?

Are you holding your breath?

Are you listening for something even while reading these words?

Don't try to fix any of it.

Simply notice.

Then ask yourself:

When was the last time I felt completely off duty?

Let the question sit there.

And then ask:

Who could watch for me—even for a little while?

Perhaps no name comes immediately.

That's okay.

We're beginning with awareness.

Because maybe rest isn't simply closing your eyes.

Maybe rest begins when your body finally believes:

Someone else is watching now.

For a moment, you can stop listening.

You can breathe.

You can be here.

Because there are two lives in this caregiving story.

And the person who has been standing guard deserves to feel safe too.

CHAPTER FIVE

Nobody Can Do It Like I Can

There is a moment that happens in many caregiving homes.

Someone offers to help.

And before they have even finished the sentence, the caregiver says:

“We're okay.”

A daughter offers to stay for the afternoon.

“No, that's all right.”

A neighbor offers to bring dinner.

“We've got plenty.”

A friend asks if you need anything from the store.

“No, we're good.”

Someone offers to sit with your spouse so you can leave the house.

And immediately you begin thinking of all the reasons that won't work.

They don't know the medications.

They don't know how to transfer him.

She gets anxious around people she doesn't know well.

He won't eat for anyone else.

They won't know what to do if something happens.

I'll have to explain everything.

It would be easier just to do it myself.

And perhaps the thought underneath all of those thoughts is:

Nobody can do it like I can.

And you may be right.

Of Course They Can't

Nobody else has lived your relationship.

Nobody else has accumulated the thousands of tiny pieces of knowledge you carry.

You know that she says she's cold when she's actually becoming anxious.

You know that he likes the television on even when he isn't watching it.

You know that she won't take the medication with water but will take it with juice.

You know which pillow goes behind his back.

You know that when she says, “I'm fine,” she probably isn't.

You know how to help him stand.

You know when to talk.

You know when not to.

You know which stories calm her.

You know what that particular look means.

Some of that knowledge was learned through years of relationship.

Some through months of caregiving.

Some through mistakes.

Some through sleepless nights.

Some through trial and error.

And some you simply know because you love this person.

So yes.

Nobody may be able to do it exactly like you.

But that doesn't mean nobody can help.

Help Doesn't Have to Look Like You

This is where caregivers can become trapped.

We unconsciously make ourselves the standard.

If another person doesn't fold the towels the same way, they aren't doing it right.

If they prepare the meal differently, the patient won't eat.

If they don't arrange the pillows correctly, we'll have to redo them.

If they don't know the routine, it's easier to do it ourselves.

And sometimes that's true.

Teaching someone can initially require more energy than simply completing the task yourself.

But there's a difference between:

They don't do it like I do.

and

They can't do it safely enough for me to step away.

Those are very different standards.

The goal isn't to find another you.

There isn't another you.

The goal is to find people who can become trustworthy enough to carry part of the weight.

The Competence Trap

Something happens when you become very good at caregiving.

People begin depending upon your competence.

You know the schedule.

You know the physicians.

You know the medications.

You know the equipment.

You know what the insurance company said.

You know where the paperwork is.

You know what happened at the last appointment.

You know what needs to happen next.

And because you know everything, everyone else gradually knows less.

They ask you.

They wait for you.

They defer to you.

Eventually the entire caregiving system begins revolving around one person.

You.

At first, that may feel efficient.

Later, it becomes dangerous.

Because the more indispensable you become, the less able you are to step away.

And the less you step away, the more indispensable you become.

It's a circle.

Competence becomes responsibility.

Responsibility becomes dependence.

Dependence becomes exhaustion.

And exhaustion makes it even harder to teach someone else.

This isn't because you did something wrong.

It simply means the caregiving system has become too dependent on one person.

"Just Tell Me What You Need"

People often say this with genuine love.

"Just tell me what you need."

It's a generous offer.

But sometimes the exhausted caregiver has absolutely no idea how to answer.

What do I need?

I need someone to understand everything without me explaining it.

I need someone to make a decision without asking me six questions.

I need someone to notice that the refrigerator is empty.

I need someone to remember that the trash goes out Tuesday.

I need someone to sit here without needing me to entertain them.

I need someone to take over without making me manage their help.

Because sometimes managing help becomes another caregiving task.

That matters.

Caregivers don't simply need willing people.

They need useful help.

Don't Ask Me What I Need—Offer Something

There may be a better way to support caregivers.

Instead of:

"Call me if you need anything."

Try:

"I'm going to the grocery store. Send me five things you need."

Or:

"I can sit with your husband Thursday from two until five. Would that help?"

Or:

"I'm bringing dinner Wednesday. Is there anything you can't eat?"

Or:

"I can mow the yard this weekend."

Or:

“I'll drive Mom to her appointment if you give me the information.”

Or simply:

“I have two hours. What can I take off your plate?”

Specific help is easier to receive than unlimited help.

The caregiver doesn't have to invent a task.

Someone has already created a doorway.

All they have to do is say:

Yes.

Sometimes that is difficult enough.

Why Is Yes So Hard?

Because accepting help can awaken uncomfortable feelings.

Guilt.

Embarrassment.

Loss of privacy.

Fear of judgment.

Fear of losing control.

Fear that someone will think you aren't managing well.

Fear that the person you love won't be cared for properly.

Or perhaps a belief you have carried your entire life:

I should be able to handle this.

But what exactly is “this”?

Managing a household?

A serious illness?

Medications?

Appointments?

Personal care?

Finances?

Nighttime supervision?

Emotional support?

Family communication?

Medical decisions?

Your own employment?

Your own health?

Your own grief?

Perhaps the problem isn't that you can't handle it.

Perhaps “it” was never supposed to be handled by one person.

Trust Has to Be Built

We shouldn't romanticize accepting help.

Not everyone who offers is actually helpful.

Some people are unreliable.

Some don't listen.

Some minimize instructions.

Some make the caregiver more anxious.

Some arrive late.

Some don't understand the patient's needs.

Some people genuinely aren't safe choices.

So accepting help doesn't mean abandoning discernment.

Trust should be earned.

Start small.

Let someone bring dinner.

Let someone pick up a prescription.

Let someone sit for thirty minutes while you're nearby.

Let someone learn one routine.

Let someone accompany you to an appointment.

See how it goes.

Help doesn't have to begin with handing someone the keys to your entire caregiving world.

It can begin with one task.

Then another.

Trust grows through experience.

Teach Someone What You Know

There is another reason to let people participate.

Someone else needs to know.

Remember what we said earlier:

One person should never be the entire emergency plan.

If you became sick tonight, could someone step in tomorrow morning?

Would they know what medications are taken?

Would they know the physician's number?

Would they know which pharmacy you use?

Would they know allergies?

Would they know where important documents are?

Would they understand the basic routine?

Would they know whom to call?

If the answer is no, that doesn't mean you've failed.

It means something important has become visible.

Perhaps part of caregiving is not simply learning how to care.

Perhaps it is also teaching someone else enough that you are allowed to be human.

Make the Invisible Visible

Caregivers carry enormous amounts of information in their heads.

That information needs somewhere else to live.

Write down the medication list.

Write down important phone numbers.

Keep appointment information together.

Write down the daily routine.

Keep emergency contacts accessible.

Document the things another person would need to know.

Not because you're expecting something bad to happen.

Because your brain deserves backup too.

Every piece of information you move out of your head is one less thing your nervous system has to guard.

You don't have to remember everything if something else remembers it for you.

A notebook can help.

A calendar can help.

A medication chart can help.

A shared family document can help.

Simple systems create breathing room.

Let Them Do It Differently

This may be harder than writing down medications.

Someone comes to help.

And they do something differently.

The towels are folded wrong.

The dishes are put in the wrong cabinet.

Your spouse's lunch is twenty minutes later than usual.

They watch a television program you would never choose.

The pillows aren't arranged perfectly.

You return and think:

That's not how I do it.

Perhaps not.

But ask another question:

Was everyone safe?

Was your loved one cared for?

Were essential needs met?

Did you get an hour away?

If so, perhaps different doesn't always mean wrong.

Sometimes accepting help requires accepting imperfection.

Not unsafe care.

Not neglect.

Just difference.

Because if people can only help when they become exactly like you, eventually nobody will qualify.

And you will remain alone.

The Gift of Being Unnecessary

That phrase may sound strange.

Caregivers spend so much time being necessary.

Someone needs you.

Someone calls your name.

Someone waits for you.

Someone depends upon you.

Being necessary can become deeply connected to love.

But imagine something for a moment.

You walk out the door.

And everything is okay.

Someone else gives the medication.

Someone else makes lunch.

Someone else answers the call from the bedroom.

Someone else sits beside the person you love.

And for two hours...

you are unnecessary.

Not unloved.

Not replaced.

Not forgotten.

Just unnecessary.

For two hours.

What might that feel like?

Perhaps frightening.

Perhaps relieving.

Perhaps both.

But there is a kind of freedom in discovering:

Everything does not fall apart when I stop holding it.

Help Protects the Relationship

There is another reason to share caregiving.

When one person becomes responsible for every task, the relationship itself can become buried beneath caregiving.

You stop being husband and wife.

You become caregiver and patient.

You stop being daughter and mother.

You become scheduler and appointment.

You stop being partners.

You become medication manager and medication recipient.

Every conversation becomes:

Did you take this?

Do you need the bathroom?

Are you hurting?

Did you eat?

How do you feel?

Sometimes bringing another person into the caregiving circle gives you the opportunity to become something else again.

For an hour, you don't have to be the aide.

You can be the wife.

You don't have to be the nurse.

You can be the husband.

You don't have to manage everything.

You can sit beside your mother and simply be her daughter.

That's not a small thing.

Help doesn't only protect the caregiver.

Sometimes it protects the relationship.

Let Love Become a Team

Perhaps caregiving was never meant to be a solo act.

Maybe the deepest form of devotion isn't:

I'll do everything for you.

Maybe it's:

I'll make sure you are cared for—even when I'm not the person doing every part of it.

That's different.

It allows love to become larger than one person's capacity.

Family.

Friends.

Neighbors.

Faith communities.

Healthcare professionals.

Hospice teams.

Aides.

Volunteers.

Community resources.

Not everyone will do everything.

But perhaps many people can do something.

One person brings dinner.

One person handles the lawn.

One person stays Tuesday afternoon.

One person makes phone calls.

One person drives to an appointment.

One person listens when you're exhausted.

And slowly the weight that was crushing one person is distributed among many hands.

The person you love is still cared for.

But now perhaps the caregiver is too.

You Are Still Irreplaceable

This is important.

Allowing someone else to help doesn't make you less important.

You are not being replaced.

Your history cannot be replaced.

Your relationship cannot be replaced.

Your voice cannot be replaced.

The way you know this person cannot be replaced.

Someone else can give medication.

Someone else can prepare lunch.

Someone else can sit beside the bed.

But they cannot become you.

You don't need to prove your importance through exhaustion.

You were important before the illness.

You are important during it.

And you will remain important whether you perform every caregiving task or not.

Perhaps the goal was never to become indispensable.

Perhaps the goal was simply to remain present.

And presence doesn't require doing everything.

A Presence Moment

Think about the sentence:

Nobody can do it like I can.

Maybe that's true.

Don't argue with it.

Don't judge yourself for it.

Just ask:

Does someone really need to do it exactly like me?

Then think about one caregiving responsibility you carry.

Just one.

Something another trustworthy person could learn.

Not everything.

One thing.

Now imagine letting them do it.

Notice what happens inside you.

Relief?

Fear?

Guilt?

Resistance?

Don't fix the feeling.

Just notice it.

Then ask:

What would become possible for me if I didn't have to do this one thing?

Maybe you would sleep.

Maybe you would see your doctor.

Maybe you would have lunch with someone.

Maybe you would sit outside.

Maybe you would simply do nothing.

And perhaps doing nothing for an hour would be enough.

Because accepting help doesn't mean someone else has taken your place.

It means someone has stepped beside you.

And maybe that's what you've needed all along.

Not someone to replace you.

Someone to stand beside you.

There are two lives in this caregiving story.

And neither one should have to carry it alone.

CHAPTER SIX

The Guilt of Leaving the Room

The help finally comes.

Someone you trust walks through the door.

They know the medications.

They know where everything is.

You've explained what needs to happen.

Your loved one is comfortable.

For the first time in days, maybe weeks, you have an opportunity to leave.

So you pick up your keys.

You put on your coat.

You walk toward the door.

And then you stop.

“Are you sure you'll be okay?”

“Yes.”

“You have my number?”

“Yes.”

“The medication is at two.”

“I know.”

“If anything changes—”

“I'll call you.”

You walk outside.

You get into the car.

And instead of feeling free, you feel terrible.

You haven't done anything wrong.

Nobody is upset with you.

Your loved one is safe.

Someone trustworthy is there.

And yet something inside you whispers:

I shouldn't be leaving.

This is one of caregiving's strangest burdens.

You can desperately need a break and then feel guilty when you finally get one.

When Relief Feels Wrong

You may have imagined this moment differently.

You thought when someone finally came to relieve you, you would feel grateful.

And you do.

But you may also feel something else.

Relief.

Deep relief.

For the next two hours, nobody needs you.

You don't have to listen.

You don't have to watch.

You don't have to manage medications.

You don't have to answer questions.

You don't have to help anyone stand.

You don't have to anticipate what might happen next.

And then comes the guilt.

Why am I so relieved to get away?

Maybe you even enjoy yourself.

You sit down at a restaurant.

Someone makes you laugh.

You walk through a store.

You sit in your car listening to music.

For a moment, you forget.

Then you remember.

And somehow even forgetting for a few minutes can feel like betrayal.

How can I be enjoying myself while the person I love is sick?

But relief is not rejection.

Enjoyment is not abandonment.

Laughter is not disloyalty.

You are allowed to experience something other than caregiving.

“What If They Need Me?”

This question follows many caregivers out the door.

What if she needs me?

What if he becomes afraid?

What if something changes?

What if the person staying with her doesn't recognize it?

What if he asks for me?

What if I should have stayed?

You may check your phone.

Then check it again.

No missed calls.

You put it down.

Two minutes later, you pick it back up.

Nothing.

You wonder whether you should call.

Just to check.

And sometimes you do.

“How's everything?”

“Fine.”

“Did she eat?”

“Yes.”

“Any pain?”

“No.”

“Are you sure?”

“Yes. Go enjoy yourself.”

So you hang up.

But part of you remains in the room you left.

Your body is at lunch.

Your mind is still caregiving.

This is why respite isn't simply about getting the caregiver out of the house.

The harder journey may be helping the caregiver believe:

I am allowed to be somewhere else.

Guilt Can Sound Like Love

Caregiver guilt is persuasive because it often speaks in the language of devotion.

If you really loved him, you'd stay.

She would stay with you.

You don't know how much time you have left.

You can go out later.

What if this is the day something happens?

These thoughts can make sacrifice feel like the only morally acceptable choice.

But love doesn't require constant physical proximity.

You can love someone from the grocery store.

You can love someone while sitting with a friend.

You can love someone while sleeping.

You can love someone while seeing your physician.

You can love someone while walking around the block.

You can even love someone while enjoying yourself.

Love doesn't disappear when you leave the room.

It goes with you.

The Fear of the Last Time

There is another fear caregivers don't always say aloud.

What if I leave...

and something happens?

What if my husband dies while I'm gone?

What if Mom takes her last breath while I'm at the store?

What if I miss it?

What if I never forgive myself?

For families caring for someone near the end of life, this fear can become enormous.

So the caregiver stays.

Hour after hour.

Sometimes day after day.

Watching.

Waiting.

Afraid to shower.

Afraid to sleep.

Afraid to walk outside.

Because perhaps this will be the moment.

And presence at the end of life can be profoundly meaningful.

But dying does not always follow our schedules or expectations.

Some people die surrounded by family.

Some die while one person holds their hand.

Some seem to die in a quiet moment after everyone has stepped away.

There is no perfect way to be present for every moment.

And if death occurs while you are outside the room, it does not erase all the moments when you were inside it.

A lifetime of presence is not invalidated by one moment of absence.

That deserves to be remembered.

You Don't Have to Earn Rest

Sometimes caregivers treat rest like a reward.

I'll sit down after I finish the laundry.

I'll go out after the appointment.

I'll sleep when she's comfortable.

I'll take a break when things calm down.

But there is always another task.

Another load of laundry.

Another phone call.

Another medication.

Another meal.

Another need.

If rest has to be earned by completing caregiving, you may never qualify for it.

Rest isn't a prize for finishing.

Rest is part of continuing.

You don't put gasoline in a car because it has earned fuel.

You put fuel in because you expect it to keep moving.

Perhaps caregivers deserve at least the same kindness.

The Person You Love May Feel Guilty Too

There is another person in this story.

The one receiving the care.

Imagine what it can feel like to watch someone you love rearrange their entire life around you.

They stop traveling.

They stop seeing friends.

They sleep beside your hospital bed.

They cancel appointments.

They become exhausted.

And you know why.

Because of your illness.

Some patients carry enormous guilt about this.

They may say:

“You don't have to stay.”

“Go home.”

“Go get something to eat.”

“I'm okay.”

“Please go sleep.”

And the caregiver responds:

“No, no. I'm fine.”

But perhaps they're trying to care for you too.

Perhaps letting you leave for an hour gives them something important:

the knowledge that their illness has not consumed your entire life.

Sometimes receiving respite isn't only a gift to the caregiver.

It can be a gift to the person being cared for.

“But They Want Me Here”

Sometimes they do.

They may become anxious when you leave.

They may ask repeatedly when you're coming back.

They may prefer you to anyone else.

They may even become upset when you go.

That makes leaving much harder.

Compassion matters here.

So do boundaries.

There is a difference between acknowledging someone's fear and allowing their fear to determine whether you are ever permitted to leave.

You can say:

“I know you want me here.”

“I love being with you.”

“I'm going to be gone for one hour.”

“Sarah is staying with you.”

“You'll be safe.”

“And I'll come back.”

Leaving doesn't have to be abrupt or uncaring.

It can be loving.

Predictable.

Reassuring.

And temporary.

Sometimes both people have to learn that separation can occur without abandonment.

Start With Ten Minutes

Maybe two hours feels impossible.

Don't start there.

Walk outside.

Sit on the porch.

Take a shower with the door closed while someone else listens.

Drive around the block.

Get coffee.

Walk through the yard.

Sit in your car.

Ten minutes.

Then come back.

Nothing terrible happened.

Try twenty.

Trust doesn't always arrive through reasoning.

Sometimes the nervous system has to experience:

I left, and everything was okay.

Again.

And again.

Eventually the door may stop feeling like a boundary you're forbidden to cross.

Where Would You Go?

Caregiving can last so long that people forget what they would even do with free time.

Someone says:

“Go do something.”

And you think:

Like what?

You don't know anymore.

You used to have hobbies.

Friends.

Places you liked to go.

Maybe you enjoyed gardening.

Fishing.

Shopping.

Reading in a coffee shop.

Walking.

Church.

Movies.

Lunch with a friend.

Working in the garage.

Sitting in a park.

But illness reorganized life.

And slowly those things disappeared.

So when respite finally arrives, don't be surprised if freedom initially feels empty.

You don't have to make your time away productive.

You don't need a self-improvement project.

You don't have to accomplish anything.

Maybe you sit somewhere.

Maybe you eat something slowly.

Maybe you drive with no destination.

Maybe you do absolutely nothing.

Rest does not need to produce anything to be valuable.

Don't Make Self-Care Another Job

Caregivers hear this phrase constantly:

“Take care of yourself.”

It can become irritating.

Because now, in addition to everything else you're responsible for, apparently you're failing at self-care too.

Exercise.

Meditate.

Eat better.

Journal.

Get eight hours of sleep.

See friends.

Practice gratitude.

Take a bath.

Go outside.

And suddenly self-care becomes another checklist.

Another standard you can't meet.

Another reason to feel inadequate.

That's not what we're talking about.

Self-care doesn't need to become another assignment.

Sometimes caring for yourself is simply allowing something to be removed.

One less responsibility.

One less hour on duty.

One less decision.

One less thing to carry.

Maybe the most compassionate question isn't:

“What should I do for myself?”

Maybe it's:

“What could I stop doing for a little while?”

Someone Else Can Hold the Room

Remember Chapter Four?

Always listening.

Always watching.

Always responsible.

Perhaps this is what respite ultimately means:

Someone else holds the room.

Someone else listens.

Someone else watches.

Someone else answers.

Someone else carries responsibility for a little while.

And you leave.

Not forever.

Not because you stopped loving.

Not because you're tired of the person.

But because you are tired.

There is a difference.

A profound one.

You can be tired of caregiving without being tired of the person you love.

Caregivers need permission to say that.

Sometimes desperately.

Come Back Without Apologizing

This may be one of the most important parts.

You return home.

You walk through the door.

Everything is okay.

Your loved one looks at you.

You don't need to say:

“I'm sorry I was gone so long.”

You don't need to justify where you went.

You don't need to feel guilty because you enjoyed yourself.

You can simply say:

“I'm back.”

And perhaps something has changed.

Not dramatically.

You aren't suddenly refreshed after one afternoon.

The illness hasn't disappeared.

The responsibilities remain.

But maybe your shoulders are slightly lower.

Maybe you breathe a little easier.

Maybe you have a little more patience.

Maybe you remember that there is still a world outside this house.

And maybe you brought a small piece of that world back inside with you.

That's what respite can do.

It doesn't remove caregiving.

It returns the caregiver to it.

The Door Swings Both Ways

Perhaps we need to change what the doorway means.

For many caregivers, the door becomes something they are afraid to walk through.

Leaving feels like abandonment.

But a door isn't only an exit.

It's also an entrance.

You leave.

And you return.

You step away.

And you come back.

You rest.

And you reenter.

The door swings both ways.

Perhaps love does too.

Love knows how to stay.

But healthy love must sometimes learn how to leave for a little while.

And then return.

Not with less devotion.

Sometimes with more capacity to express it.

A Presence Moment

Imagine yourself standing at the door.

Someone trustworthy is with the person you love.

Everything important has been explained.

You have your keys.

You have an hour.

Notice what happens inside you.

What thought makes it hardest to leave?

Is it:

What if something happens?

Is it:

They need me.

Is it:

I shouldn't want to get away.

Is it:

What will people think?

Or perhaps:

What if I enjoy being gone?

Don't argue with the thought.

Just notice it.

Then place another sentence beside it:

Leaving for a little while does not mean I am leaving the person I love.

Read it again.

Leaving for a little while does not mean I am leaving the person I love.

Maybe today you don't need an afternoon.

Maybe you need ten minutes.

Step outside.

Feel the air.

Let someone else listen.

Let someone else watch.

Let someone else hold the room.

And when you're ready, come back.

No apology.

No explanation.

Just:

“I'm back.”

Because there are two lives in this caregiving story.

Sometimes loving both of them means staying.

And sometimes...

it means walking through the door.

CHAPTER SEVEN

When Your World Gets Smaller

It usually doesn't happen all at once.

Nobody wakes up one morning and decides:

I'm going to stop having a life.

It happens quietly.

You decline dinner because your husband isn't having a good day.

You miss church because your mother was awake most of the night.

You stop going to your book club because leaving has become complicated.

You tell a friend:

“Maybe next week.”

Then next week comes.

And something else happens.

Eventually people stop asking.

Not because they stopped caring.

Sometimes they simply assume you're unavailable.

And perhaps you are.

Your world begins shrinking.

The restaurant you used to visit becomes the kitchen table.

The vacation you were planning becomes a series of medical appointments.

The friends you used to see become names on your phone.

The bedroom becomes a place for medical equipment.

The living room becomes a care space.

The calendar fills with appointments instead of plans.

The person you love is still there.

You are still there.

But somehow the life you shared has become smaller.

Illness has moved into the house.

And slowly, without asking permission, it begins rearranging everything.

The Invitations Stop Coming

At first, people invite you.

“Come to dinner.”

“We're getting together Saturday.”

“Do you want to go with us?”

And you say no.

Not because you don't want to go.

Because you can't.

Or because leaving requires more planning than the outing seems worth.

Someone has to stay.

Medications have to be arranged.

Meals have to be prepared.

You have to explain everything.

You worry the entire time you're gone.

So eventually:

“No, thank you.”

becomes easier than:

“I'll try.”

After enough refusals, invitations become less frequent.

And one day you see pictures.

Your friends went somewhere.

Everyone was there.

Except you.

And it hurts.

Even though you probably couldn't have gone.

Even though you would have said no.

It still hurts not to be asked.

This is one of the strange contradictions of caregiving.

You can be unable to participate and still desperately want to be remembered.

“How Are Things?”

People mean well.

They ask:

“How are things?”

And you don't know how to answer.

Do they want the real answer?

Do they have forty-five minutes?

Do they want to know about the fall Tuesday night?

The medication change?

The confusion?

The insurance problem?

The argument with your sibling?

The fact that you cried in the shower this morning?

Probably not.

So you say:

“We're hanging in there.”

Or:

“About the same.”

Or:

“Taking it one day at a time.”

Then you ask about them.

Because sometimes explaining your life is more exhausting than living it.

Eventually conversations become shorter.

Not because you have nothing to say.

But because caregiving has given you too much to say.

When Other People's Problems Feel Strange

Caregiving can alter your sense of proportion.

Someone complains that the restaurant got their order wrong.

Someone is furious because their flight was delayed.

Someone is upset about a minor inconvenience at work.

And you listen.

But somewhere inside you think:

You have no idea.

You were awake at three this morning helping someone breathe.

You spent yesterday discussing whether a medication should be increased.

You watched the person you love struggle to walk across a room.

Suddenly ordinary frustrations can feel very far away.

That can create distance.

Not because you're better than anyone.

Not because their problems don't matter.

Your world has simply changed.

You are living closer to vulnerability.

Closer to uncertainty.

Closer to mortality.

And sometimes it's difficult to move back and forth between those worlds.

Some People Disappear

Illness reveals things about relationships.

Some people move closer.

Others move away.

Sometimes people don't know what to say.

They are afraid of illness.

Afraid of dying.

Afraid they'll say the wrong thing.

Afraid of intruding.

So they do nothing.

Weeks pass.

Then months.

And the caregiver notices.

Where did everybody go?

That question can hurt deeply.

Especially when you remember all the times you showed up for others.

There may be disappointment.

Anger.

Even resentment.

Those feelings are understandable.

But sometimes people aren't absent because they don't care.

They are absent because they don't know how to enter a world they don't understand.

Perhaps they need an invitation.

Not:

“Come fix this.”

Just:

“Come sit with us.”

Sometimes presence is the help.

And Some People Surprise You

Then there are others.

The neighbor you barely knew who starts taking your trash cans to the curb.

The coworker who brings dinner.

The friend who texts every Tuesday without expecting an answer.

The person who sits with your spouse so you can get a haircut.

The nurse who remembers your name.

The aide who notices you're exhausted.

The person who doesn't say:

“Let me know if you need anything.”

They simply show up with something useful.

Caregiving can shrink your world.

But strangely, it can also reveal a different one.

A quieter community.

People you didn't know would become important.

People who don't need explanations.

People who know how to sit in uncomfortable places.

People who understand that sometimes the greatest gift isn't advice.

It's consistency.

When Marriage Changes Shape

Sometimes the caregiver is caring for a spouse.

That creates a particular kind of grief.

The person is still your husband.

Still your wife.

Still your partner.

But the relationship may no longer feel the same.

Maybe you used to travel together.

Now leaving the house requires equipment.

Maybe you slept beside each other for forty years.

Now one of you sleeps in a hospital bed.

Maybe your evenings once ended with conversation.

Now they end with medications.

Maybe intimacy has changed.

Touch has changed.

Sexuality has changed.

Roles have changed.

One person who was once an equal partner may now need help bathing, dressing, eating, or using the bathroom.

Love remains.

But the shape of love changes.

And caregivers can grieve that change while still being grateful the person is alive.

Those feelings do not contradict each other.

You can treasure the person who remains...

and miss the relationship you once had with them.

When You Become More Caregiver Than Spouse

This can happen almost without noticing.

You stop asking:

“What do you want to do tonight?”

and start asking:

“Did you take your medication?”

You stop talking about vacations.

You talk about appointments.

You stop holding hands while walking somewhere.

You hold an arm to prevent a fall.

You stop lying beside each other.

You reposition pillows.

You adjust blankets.

You check oxygen.

Caregiving tasks begin consuming the relationship.

And sometimes the caregiver desperately misses simply being a husband or wife.

This is why help matters.

If someone else can perform a caregiving task, even briefly, perhaps you can reclaim something.

Sit beside your spouse without doing anything.

Hold their hand without checking a pulse.

Watch the movie.

Look through old photographs.

Talk about something unrelated to illness.

Be married.

Even for twenty minutes.

The diagnosis may have entered your marriage.

It does not have to become the entire marriage.

The Sandwich in the Middle

For adult children, caregiving can create another kind of shrinking world.

You may be raising children while caring for parents.

Your teenager needs help with homework.

Your mother needs groceries.

Your boss needs a report.

Your father has an appointment.

Dinner needs to be made.

The school calls.

The pharmacy calls.

Your sibling calls.

Everyone needs something.

And you are in the middle.

People sometimes call this the sandwich generation.

But that phrase can sound almost playful.

There is nothing playful about feeling pulled between generations you love.

You may feel guilty when you're with your parent because your children need you.

Then guilty when you're with your children because your parent needs you.

You are physically present in one place while mentally living in another.

There is no location where everyone has what they need.

Including you.

Work Doesn't Stop Because Someone Is Sick

Then there is employment.

Bills continue arriving.

Mortgages still exist.

Groceries still cost money.

Insurance still has rules.

So caregivers go to work.

Sometimes after being awake half the night.

They sit in meetings while waiting for a physician to call.

They answer emails from hospital rooms.

They use lunch breaks to schedule appointments.

They take personal days.

Then sick days.

Then unpaid days.

They arrive late.

Leave early.

Turn down opportunities.

Reduce hours.

Sometimes they leave work entirely.

And with that can come another loss.

Not simply income.

Identity.

Colleagues.

Purpose.

Professional confidence.

Retirement savings.

Future plans.

Caregiving doesn't happen in an economic vacuum.

Love may be freely given.

Caregiving is rarely free.

The Bills Nobody Talks About

Gasoline.

Parking.

Medical supplies.

Meals away from home.

Home modifications.

Equipment.

Prescription costs.

Lost wages.

Childcare.

Transportation.

People often absorb these expenses one at a time.

Twenty dollars here.

Fifty there.

A missed shift.

A copay.

Another tank of gas.

A hotel near the hospital.

A wheelchair ramp.

A bathroom modification.

Individually, each expense may seem manageable.

Together, they can become enormous.

And caregivers sometimes feel ashamed to talk about money.

As though placing a dollar sign anywhere near love makes the love less pure.

It doesn't.

Financial strain is real.

And worrying about money while someone you love is sick does not make you selfish.

It makes you someone living in the real world.

"We Don't Want to Be a Burden"

This sentence appears everywhere in caregiving.

The patient says it.

The caregiver says it.

The family says it.

Nobody wants to inconvenience anyone.

So everyone tries to manage privately.

But human beings were never designed to be entirely self-contained.

We need one another.

There are seasons when we give.

And seasons when we receive.

Sometimes the person who brought you dinner today will need you five years from now.

Community isn't a ledger.

It's a circulation of care.

Perhaps needing people doesn't make you a burden.

Perhaps it simply makes you part of a human family.

Protect One Piece of Your World

You may not be able to preserve everything.

Some seasons really do require sacrifice.

The weekly golf game may not be possible.

Travel may have to wait.

Work may need to change.

Social life may become smaller.

But perhaps not everything has to disappear.

Protect one thing.

One friendship.

One walk.

One cup of coffee on Saturday.

One phone call.

One faith community.

One hobby.

One hour.

Something that reminds you:

I still exist outside caregiving.

This isn't about refusing reality.

It's about preserving a thread connecting you to yourself.

Because one day caregiving will change.

Perhaps gradually.

Perhaps suddenly.

And when it does, you will need that thread.

Keep the Door Open to the World

Isolation has a way of becoming self-reinforcing.

The longer you stay home, the harder leaving can feel.

The less you talk to people, the harder explaining yourself becomes.

The fewer invitations you accept, the fewer invitations arrive.

So perhaps you don't need to reenter the entire world.

Just keep the door cracked open.

Answer the text.

Let the friend visit.

Sit on the porch with the neighbor.

Attend something for thirty minutes.

Make the phone call.

Tell someone the truth when they ask:

“How are you?”

Maybe not everything.

Just a little more truth than:

“Fine.”

Connection doesn't require pretending your life is normal.

It requires allowing someone to meet you where life actually is.

You Are Still Part of the World

Illness can make a household feel like its own universe.

Everyone else continues living.

People go on vacations.

Children graduate.

Friends celebrate anniversaries.

Seasons change.

Restaurants open.

Movies come out.

Neighbors move.

Life continues outside the window.

Meanwhile, your days can begin looking almost identical.

Medication.

Meals.

Appointments.

Laundry.

Phone calls.

Waiting.

Watching.

Sleeping.

Beginning again.

It can feel as though the world has moved forward without you.

It hasn't.

There is still a place for you in it.

Maybe you can't occupy that place the way you once did.

Not right now.

But you still belong.

You are still a friend.

Still a neighbor.

Still a colleague.

Still a sibling.

Still a parent.

Still a spouse.

Still a person with interests.

Still a person with ideas.

Still someone capable of laughter.

Still someone with a future.

Caregiving has changed your life.

It has not erased it.

Let Your World Be Small Without Becoming Empty

There are seasons when life really does become small.

Maybe that's not entirely something to fight.

There can be beauty in a smaller world.

A cup of coffee together.

A hand held in silence.

Sunlight coming through the window.

A familiar television show.

A conversation.

A meal.

A visitor.

A quiet afternoon.

When illness strips away the unnecessary, small things can become sacred.

The goal isn't necessarily to make life big again.

Maybe the goal is to keep the smaller life from becoming empty.

Fill it with people who matter.

Moments that matter.

Rest.

Laughter when it comes.

Honesty.

Memory.

Music.

Touch.

Presence.

You may not be able to travel very far.

But there can still be life in the room.

A Presence Moment

Think about your world before caregiving became such a large part of it.

Who did you see?

Where did you go?

What did you enjoy?

What made you feel like yourself?

Don't use those memories to make yourself sad.

Just notice.

Now ask:

What part of my world do I miss most?

A person?

A place?

An activity?

A feeling?

Maybe the answer surprises you.

Now ask something smaller:

Is there one piece of that world I could bring back into my life as it is today?

Not when caregiving ends.

Not someday.

Today.

Could the friend come to you?

Could the music play in this room?

Could the hobby become smaller?

Could you make the phone call?

Could someone sit with your loved one while you go somewhere for thirty minutes?

Could you simply tell someone:

“I miss you.”

You don't have to rebuild your whole world.

Just protect one small piece of it.

Because caregiving may have made your world smaller.

It does not have to make you disappear from it.

There are two lives in this caregiving story.

And both of them still belong to the world.

CHAPTER EIGHT

When the Caregiver Becomes the Patient

There are two people in the room.

We have said that from the beginning.

One of them has a diagnosis.

Their medications are listed.

Their blood pressure is checked.

Their appointments are scheduled.

Their symptoms are discussed.

People ask whether they are eating.

Sleeping.

Hurting.

Breathing comfortably.

Taking their medications.

Everyone knows this person is vulnerable.

And then there is the person standing beside the bed.

The wife.

The husband.

The daughter.

The son.

The granddaughter.

The grandson.

The friend.

The caregiver.

Nobody has checked their blood pressure.

Nobody knows when they last saw their doctor.

Nobody has asked whether they filled their own prescriptions.

Nobody knows about the headache they've had for three weeks.

Or the pain they've been ignoring.

Or the weight they've lost.

Or the exhaustion they have learned to call normal.

Everyone is watching the patient.

But perhaps there really are two patients in the room.

One of them simply hasn't been diagnosed yet.

"I'll Deal With It Later"

It begins innocently.

You have a doctor's appointment Tuesday.

Then your husband has a difficult night Monday.

So you cancel.

You'll reschedule.

Your mammogram reminder arrives.

But Mom has three appointments this month.

You'll do it next month.

Your knee has been bothering you.

But Dad can't be left alone.

You'll get it checked eventually.

You haven't had bloodwork in a while.

You know you should.

But there is so much going on.

Later.

Later.

Later.

Caregiving has a way of making later sound reasonable.

And sometimes it is.

Emergencies happen.

Appointments need to be moved.

Life is complicated.

But there is a difference between postponing something...

and disappearing from your own healthcare.

The Symptom You Keep Explaining Away

Maybe it isn't a routine appointment.

Maybe your body is actually trying to tell you something.

You're more tired than usual.

Of course I'm tired. I'm caregiving.

You're short of breath.

I'm out of shape.

You've been getting headaches.

It's stress.

Your stomach hurts.

I'm not eating properly.

You've lost weight.

I've been too busy to eat.

Your blood pressure is high.

Anyone's would be with what I'm dealing with.

You're having chest discomfort.

Probably anxiety.

Something feels different.

But every symptom has an explanation.

And some of those explanations may even be correct.

Stress can affect the body.

Sleep deprivation can make you feel terrible.

Poor nutrition matters.

But there is a dangerous question hiding inside those explanations:

What if it isn't only stress?

You don't have to know.

That's why we have doctors.

Please Don't Diagnose Yourself With Caregiving

Caregivers become extraordinarily knowledgeable.

You learn medical terminology you never wanted to know.

You learn medications.

Symptoms.

Equipment.

Insurance.

Disease progression.

You learn when something doesn't look right.

But there is one patient you may not be seeing clearly.

Yourself.

Because when it comes to your own body, you may become remarkably good at minimizing.

“It's nothing.”

“I'm fine.”

“It'll pass.”

“I don't have time for this.”

“I'll call the doctor if it gets worse.”

Those phrases deserve our attention.

Because sometimes “I'm fine” doesn't mean I'm fine.

Sometimes it means:

I cannot afford emotionally or practically for something to be wrong with me too.

That is understandable.

But your body doesn't negotiate with your schedule.

What Happens If You Go Down?

This isn't meant to frighten you.

It's meant to ask an important practical question.

If you became ill tomorrow, what would happen?

Who would care for your spouse?

Who would take Mom to the appointment?

Who knows Dad's medications?

Who knows the routine?

Who would answer the phone?

Who would manage the household?

Caregivers sometimes believe taking time for their own health competes with caring for their loved one.

But perhaps the opposite is true.

Taking care of your health is part of the care plan.

Your doctor's appointment isn't separate from caregiving.

Your mammogram isn't separate from caregiving.

Your blood pressure isn't separate from caregiving.

Your colon screening isn't separate from caregiving.

Your dental health isn't separate from caregiving.

Your medications aren't separate from caregiving.

Your sleep isn't separate from caregiving.

Because the caregiving plan depends heavily upon something everyone may be taking for granted:

you remaining well enough to continue.

Keep the Appointment

Maybe this chapter only needs to convince you of one thing.

Keep the appointment.

The routine physical.

The follow-up.

The screening.

The lab work.

The dental appointment.

The eye examination.

The specialist appointment you've already postponed twice.

Put it on the calendar.

Then treat it as though it belongs to the person you are caring for.

Would you cancel their oncology appointment because laundry needed to be done?

Would you skip their cardiology appointment because nobody could mow the lawn?

Would you ignore their new symptom because the week was busy?

Probably not.

So perhaps your appointment deserves a similar priority.

You don't need to feel important enough.

You don't need to earn it.

Your health is reason enough.

Tell Your Doctor You Are a Caregiver

When you finally sit in the examination room and the doctor asks:

“How have you been?”

Don't automatically say:

“Fine.”

Tell them.

“My husband has been very ill and I'm his primary caregiver.”

“I'm taking care of my mother and I'm exhausted.”

“I haven't been sleeping.”

“I've been skipping meals.”

“I've been under enormous stress.”

“I've had to cancel several appointments because I can't leave my wife.”

That information matters.

Caregiving isn't simply something happening in your schedule.

It is part of the context of your health.

Your healthcare provider needs to know what your life actually looks like.

And if something has changed physically, say that too.

Don't minimize it because someone else is sicker.

Another person's diagnosis does not make your symptoms less real.

“But Who Will Stay With Them?”

This may be the most practical obstacle of all.

You aren't avoiding your doctor because you don't care about your health.

You genuinely cannot figure out how to leave.

Then your own healthcare appointment needs to become a caregiving task the family helps solve.

Ask the daughter.

Ask the son.

Ask the neighbor.

Ask the friend.

Ask your faith community.

Ask what respite resources are available.

If hospice or another care organization is involved, talk with the team about your situation and what support may be available.

If someone says:

“Let me know if there's anything I can do,”

here is an answer:

“Yes. I need to go to my doctor Thursday. Can you stay with him for two hours?”

That is a real need.

Let someone meet it.

Don't Wait for a Crisis to Give Yourself Permission

This is where caregiving can become cruel.

The caregiver may finally receive attention only after something happens.

They faint.

They fall.

Their blood pressure becomes dangerously high.

They end up in the emergency room.

A neglected problem becomes impossible to ignore.

Suddenly everyone says:

“You need to take care of yourself!”

But why did it require a crisis?

Why couldn't the routine appointment have mattered?

Why couldn't the symptom have mattered when it first appeared?

Why did the caregiver have to become visibly sick before their health became legitimate?

You do not need an emergency to qualify for care.

Read that again.

You do not need an emergency to qualify for care.

Two Appointments Belong on the Calendar

Maybe we need a very simple caregiving rule.

When the patient's appointments are being scheduled, look at the caregiver's calendar too.

When is your physical?

When was your last screening?

When was your last dental visit?

Are you overdue for anything your healthcare professional has recommended for you?

Do you need medication refills?

Is there something you've been putting off?

Write it down.

Not someday.

Put a date beside it.

A calendar reveals priorities.

And in caregiving homes, one person's name can eventually occupy every square.

Put your name back on the calendar.

There are two lives here.

When the Caregiver Is Older Too

This becomes especially important when spouses are aging together.

The person providing care may be seventy.

Seventy-five.

Eighty.

Maybe older.

They may already have their own health concerns.

Arthritis.

Diabetes.

Heart disease.

Balance problems.

Vision changes.

Hearing difficulties.

Back pain.

Medication needs.

And now they are lifting.

Repositioning.

Losing sleep.

Managing equipment.

Walking back and forth throughout the night.

Helping another person get to the bathroom.

Driving to appointments.

The assumption that one older spouse can indefinitely absorb the physical demands of caring for another older spouse deserves examination.

Love may be strong.

The body still has limits.

Sons and Daughters Aren't Invincible Either

Younger caregivers may make a different mistake.

They assume:

I'm healthy. I can handle it.

So they run.

Work.

Children.

Parents.

Appointments.

Hospitals.

Phone calls.

School activities.

Meals.

Bills.

They sleep five hours.

Eat in the car.

Miss exercise.

Cancel their physical.

Ignore symptoms.

And continue.

Because they're younger.

Because someone needs them.

Because there's no time.

But younger doesn't mean limitless.

A forty-five-year-old caregiver still has a body.

A thirty-five-year-old caregiver still needs healthcare.

A fifty-year-old daughter caring for both children and parents doesn't receive an exemption from her own health risks because her schedule is full.

Nobody does.

Your Body Has Been With You the Whole Time

Your body has carried you through every night.

Every hospital visit.

Every appointment.

Every difficult conversation.

Every transfer.

Every medication alarm.

Every emergency.

Every tear.

Every mile driven.

Every meal missed.

Every hour of sleep interrupted.

It has been there.

Quietly carrying the caregiver while the caregiver carries someone else.

Perhaps it deserves your attention too.

Not because you should become frightened about your health.

Not because every ache means something terrible.

But because your body is not merely the vehicle transporting you from one caregiving task to another.

It is your life.

There May Come a Day After Caregiving

This can be difficult to think about.

But caregiving changes.

Sometimes the person improves.

Sometimes care moves somewhere else.

Sometimes another family member takes over.

Sometimes the caregiving journey ends because the person we love dies.

And then?

There is a life afterward.

A grieving life, perhaps.

A changed life.

A life you didn't ask for.

But still a life.

You deserve to arrive there with as much of your own health intact as possible.

Not because you loved less.

Because your life matters too.

Perhaps one of the greatest gifts you can give the person you're caring for is this:

I will try not to disappear while loving you.

A Presence Moment

Think about your own healthcare.

Not the person you're caring for.

Yours.

When was the last time you had a routine checkup?

Is there a screening you've postponed?

A prescription you haven't refilled?

A dental appointment you've canceled?

A symptom you've been explaining away?

Something you've quietly thought:

I should probably get that checked.

Don't panic.

Don't diagnose yourself.

Don't search for the worst possibility.

Just notice.

Now ask:

What is one responsible thing I can do for my own health?

Maybe it's scheduling an appointment.

Maybe it's keeping one that's already scheduled.

Maybe it's telling your doctor how exhausted you really are.

Maybe it's asking someone to stay with your loved one while you go.

Maybe it's simply putting your name back on the calendar.

And when the guilt comes, remember:

You aren't taking care away from someone you love.

You are extending care to the other person in this story.

You.

Because there are two lives in this room.

Two bodies.

Two stories.

Two people worthy of attention.

Don't wait until the caregiver becomes the patient before we finally begin caring for them.

Perhaps we can begin now.

CHAPTER NINE

I Love You, But This Is Hard

There are things caregivers say out loud.

“I love him.”

“I'll do whatever she needs.”

“We'll get through this.”

“I'm grateful I can be here.”

And then there are things caregivers sometimes think but are afraid to say.

I'm tired.

I'm angry.

I don't want to do this today.

I miss my old life.

I wish someone else would take over.

I need this to stop.

And then immediately:

What kind of person thinks that?

So the thought gets buried.

You straighten the blanket.

Give the medication.

Answer the phone.

Make the meal.

Smile when someone visits.

And keep going.

Because you love this person.

Deeply.

But here is something caregivers desperately need permission to know:

You can love someone completely and still find caring for them incredibly difficult.

Those truths can live in the same room.

Love Does Not Make You Tireless

We sometimes tell beautiful stories about caregiving.

A husband faithfully caring for his wife.

A daughter devoted to her mother.

A mother caring for a disabled child.

A granddaughter moving in with her grandfather.

And those stories deserve to be honored.

But sometimes we romanticize devotion so much that we accidentally remove the humanity of the person providing it.

Love does not make muscles stop aching.

Love does not eliminate sleep deprivation.

Love does not make changing sheets at three in the morning easy.

Love does not make difficult behaviors painless.

Love does not eliminate frustration.

Love does not magically replenish patience.

Love does not make the human body inexhaustible.

Sometimes love is present precisely while all those other things are present too.

“I Shouldn't Feel This Way”

Caregivers use the word should frequently.

I should be more patient.

I should be grateful.

I should handle this better.

I shouldn't get frustrated.

I shouldn't want time away.

I shouldn't be angry.

I shouldn't feel resentful.

I shouldn't complain.

After all...

They're the one who's sick.

That sentence can silence an entire emotional life.

Yes.

The person you love may be suffering enormously.

And their suffering matters.

But suffering is not a competition.

Their pain doesn't eliminate yours.

Their diagnosis doesn't make your exhaustion imaginary.

Their fear doesn't mean you aren't frightened.

Their losses don't erase yours.

Two people can hurt at the same time.

There are two lives in this room.

Remember?

The Anger Nobody Talks About

Caregivers can become angry.

Not always.

But often enough that we should stop pretending otherwise.

You may become angry at the disease.

At the healthcare system.

At insurance.

At family members who aren't helping.

At friends who disappeared.

At the doctor who didn't call back.

At the sibling who has many opinions but never comes over.

At the medication that isn't working.

At your own body for being tired.

Sometimes...

you may even become angry at the person you're caring for.

And that can be the hardest anger to admit.

They ask you the same question for the tenth time.

They refuse the medication.

They won't use the walker.

They call you from the other room five minutes after you sat down.

They criticize the food you prepared.

They become demanding.

Or confused.

Or frightened.

Or irritable.

And something inside you says:

I can't do this anymore.

Then guilt arrives.

Sometimes the Disease Is Talking

Illness can change behavior.

Pain changes people.

Fear changes people.

Dementia can change personality and judgment.

Medications can affect mood or cognition.

Loss of independence can create anger.

Someone who once cared for themselves may now need help with intimate tasks.

That can be humiliating.

They may direct frustration toward the safest person in the room.

You.

Understanding this can help.

But understanding doesn't mean nothing hurts.

You can recognize that your mother's confusion is causing her words...

and still be hurt by the words.

You can understand that your husband is frightened...

and still feel exhausted by his demands.

Compassion for their condition does not require denying your own emotional experience.

The Bathroom Door

Sometimes the only private place left is the bathroom.

You close the door.

Maybe lock it.

Sit down.

And for three minutes, nobody can see you.

Perhaps you cry.

Perhaps you stare at the wall.

Perhaps you scroll through your phone.

Perhaps you simply breathe.

Then:

“Mom?”

“Are you in there?”

“Can you help me?”

And you're back.

Caregivers become skilled at having very small breakdowns.

Five minutes.

Three minutes.

Thirty seconds.

Then they wipe their face and return.

That ability to keep functioning can look like strength.

And it is.

But functioning isn't the same as being okay.

Resentment Doesn't Mean You Stopped Loving

This may be difficult to hear.

Sometimes caregivers feel resentful.

Not because they wanted the person to become ill.

Not because they blame them.

But because caregiving has cost something.

Maybe you left a job.

Canceled a vacation.

Lost friendships.

Changed your retirement plans.

Stopped sleeping in your own bed.

Moved across the country.

Spent savings.

Gave up privacy.

Changed your entire routine.

And perhaps nobody asked whether you wanted to.

Life simply happened.

You stepped forward because someone you loved needed you.

But sacrifice can still hurt even when it is willingly made.

You can choose something...

and grieve what the choice cost you.

That isn't selfish.

It's honest.

"Why Me?"

Maybe you've thought it.

Why am I the one doing everything?

Why doesn't my brother help?

Why doesn't her sister come?

Why am I the one making every appointment?

Why does everyone call me?

Why does everybody get to go home?

Why is my life the one that changed?

These questions may not have satisfying answers.

Families rarely divide caregiving evenly.

Often one person becomes the caregiver because they live closest.

Or they don't have children.

Or they're retired.

Or they're the daughter.

Or they're the nurse in the family.

Or they're simply the person who said yes first.

Then the temporary arrangement becomes permanent.

If you're carrying more than your share, acknowledging that isn't betrayal.

It may be the beginning of asking for change.

The Sibling Who Has Advice

Nearly every caregiving family seems to have someone who lives farther away but knows exactly what should be done.

“Have you asked the doctor about...?”

“Mom shouldn't be eating that.”

“I don't think Dad should be alone.”

“You really need to...”

Meanwhile, you are the person there at two in the morning.

You know what happened yesterday.

You know what the doctor actually said.

You know what Mom will and won't tolerate.

Advice from a distance can feel very different from help.

Sometimes the appropriate response is not an argument.

It is an invitation.

“That's a good idea. When can you come help me do it?”

Caregiving becomes clearer when opinions are given a calendar.

You May Miss Who They Used to Be

One of the deepest forms of caregiver grief occurs while the person is still alive.

Your husband is sitting beside you.

But perhaps he no longer remembers the story you've told together for forty years.

Your mother is still here.

But she no longer recognizes you every day.

Your father still speaks.

But illness has changed his personality.

Your wife is beside you.

But the relationship you once shared has been transformed by disease.

You can miss someone who is still physically present.

This is sometimes called anticipatory grief.

But whatever we call it, the experience is real.

You may look directly at someone you love and think:

I miss you.

And then feel guilty because they're sitting right there.

There is nothing wrong with you.

You are grieving change.

The Thought That Frightens Caregivers Most

There is another thought some caregivers are terrified to admit.

Especially when caring for someone with advanced illness.

I just want this to be over.

The moment it appears, guilt can be crushing.

Because the caregiver interprets it as:

I want them to die.

But that may not be what the heart is saying at all.

Perhaps you want the suffering to end.

Their suffering.

Your suffering.

The sleepless nights.

The emergencies.

The fear.

The watching.

The uncertainty.

You may want peace.

And when someone you love is approaching the end of life, wanting peace is not the same as wanting them gone.

Sometimes love itself whispers:

I don't want you to suffer anymore.

And sometimes exhaustion whispers:

I don't know how much longer I can do this.

Both deserve compassion.

Don't Confess Every Feeling to the Patient

Honesty matters.

But emotional honesty does not mean placing every difficult feeling onto the person you're caring for.

You need somewhere safe for these emotions.

A trusted friend.

A chaplain.

A counselor.

A support group.

A family member capable of listening without judgment.

A journal.

A quiet place where you can tell the truth.

There is a difference between acknowledging:

“I'm overwhelmed and sometimes resentful.”

and saying to a frightened, dependent loved one:

“You've ruined my life.”

The caregiver needs permission to tell the truth.

But truth also needs a safe container.

Find One Person You Don't Have to Protect

Caregivers spend enormous energy protecting other people.

You protect the patient from your fear.

You protect the children from how serious things are.

You protect your siblings from your frustration.

You protect friends from uncomfortable details.

You protect coworkers from knowing how exhausted you are.

Sometimes you even protect healthcare professionals by saying:

“We're managing.”

Find one person you don't have to protect.

One person who can hear:

“I'm exhausted.”

“I'm angry.”

“I'm scared.”

“I don't know if I can keep doing this.”

“I love her, but this is destroying me.”

And who doesn't immediately correct you.

Or shame you.

Or give you a lecture about gratitude.

They simply say:

“I hear you.”

That kind of presence can keep a person from becoming completely alone inside caregiving.

Your Emotions Are Information

Feelings aren't always instructions.

Being angry doesn't mean you should act angrily.

Feeling like running away doesn't mean you should abandon someone.

Feeling resentful doesn't mean your relationship is broken.

But emotions can tell us something.

Anger may be saying:

Something needs to change.

Resentment may be saying:

I'm carrying too much.

Anxiety may be saying:

I don't feel safe or prepared.

Sadness may be saying:

I'm losing something important.

Exhaustion may be saying:

I need relief.

Instead of asking:

“What's wrong with me for feeling this?”

perhaps ask:

“What is this feeling trying to tell me?”

When Anger Becomes a Warning

There is an important distinction here.

Frustration is human.

Anger is human.

But if you find yourself becoming so overwhelmed that you are afraid you may yell uncontrollably, handle someone roughly, neglect essential care, or hurt yourself or the person you're caring for, that is no longer something to simply push through.

Step away if the person can be left safely.

Call someone.

Ask another person to take over.

Contact the care team.

Get help.

There is no shame in recognizing:

I have reached my limit.

Limits are not moral failures.

They are information.

Sometimes asking for help is the action that protects both people in the room.

You Are Allowed to Have a Bad Day

Some days you will handle caregiving beautifully.

You will be patient.

Tender.

Present.

You will say the right thing.

You will feel grateful for the time together.

Other days...

you won't.

You will be irritated.

You will sigh.

You may speak too sharply.

You may cry over something small.

You may wish you were somewhere else.

You may order dinner because you cannot cook one more meal.

You may sit in the driveway for five extra minutes before going inside.

One difficult day does not define your love.

Neither does one impatient moment.

Repair what needs repairing.

Apologize when necessary.

Ask for help.

And begin again.

Caregivers are human beings.

Not saints carved from stone.

Love Can Tell the Truth

Maybe we've made love too fragile.

We imagine that if we acknowledge frustration, love somehow becomes less pure.

But mature love can hold complexity.

I love you.

And I'm tired.

I love you.

And I miss our old life.

I love you.

And I'm angry this happened.

I love you.

And I need help.

I love you.

And I need to leave the house today.

I love you.

And I'm scared.

I love you.

And this is hard.

Perhaps the word and is one of the most important words a caregiver can learn.

Not but.

“I love you, but I'm exhausted.”

The but almost cancels what came before it.

Try and.

I love you, and I'm exhausted.

Both are true.

Neither has to erase the other.

A Presence Moment

Finish this sentence quietly:

I love the person I'm caring for, and...

Don't edit the answer.

Maybe:

I'm tired.

I'm scared.

I'm angry.

I'm lonely.

I miss them.

I miss myself.

I need help.

I wish things were different.

I don't know how long I can keep doing this.

Or perhaps:

I'm grateful.

I'm honored to be here.

I'm surprised by how much this experience has changed me.

Whatever comes, let it be there for a moment.

You don't have to judge it.

You don't have to fix it.

You don't have to tell anyone yet.

Just tell yourself the truth.

Then place your hand somewhere you can feel your own body.

Your chest.

Your arm.

Your face.

And remember:

There is a person here too.

A tired person perhaps.

A frightened person.

A loving person.

An imperfect person.

A person doing something extraordinarily difficult.

You don't have to become emotionless to be a good caregiver.

You don't have to stop being human to prove that you love someone.

Maybe today you can give yourself permission to say:

I love you.

And this is hard.

Both are true.

There are two lives in this caregiving story.

And both deserve somewhere safe to tell the truth.

CHAPTER TEN

When Love Cannot Fix It

Caregivers are fixers.

Maybe you never thought of yourself that way.

But caregiving teaches you to solve problems.

The medication is running low.

You refill it.

The appointment needs to be changed.

You call.

The walker isn't working properly.

You figure it out.

They aren't eating.

You find something they might like.

They're uncomfortable.

You reposition them.

They're cold.

You find another blanket.

Something hurts.

You look for relief.

Something changes.

You call someone.

Day after day, caregiving becomes a thousand small acts of trying to make something better.

And then sometimes you reach a place where something cannot be made better.

The disease progresses.

The treatment stops working.

The body becomes weaker.

The person sleeps more.

They eat less.

The physician begins using different words.

Comfort.

Quality of life.

Hospice.

Time.

And suddenly the caregiver faces one of the hardest truths love will ever encounter:

There are things love cannot fix.

That doesn't mean love has failed.

It may mean love is being asked to become something different.

"There Has to Be Something Else"

This is an understandable response.

Another medication.

Another treatment.

Another doctor.

Another hospital.

Another opinion.

Another therapy.

Another possibility.

When you love someone, doing something feels better than doing nothing.

Action gives us hope.

So we search.

Research.

Call.

Ask.

Google.

Pray.

Try.

Sometimes another option exists.

Sometimes it helps.

And seeking appropriate treatment is not wrong.

But there can come a point when the question changes.

It may no longer be:

“What else can we do to stop this?”

It may become:

“What can we do to make this time as comfortable and meaningful as possible?”

That is not giving up.

It is a different kind of care.

The Words Nobody Wants to Hear

Perhaps a physician says:

“The treatment isn't working anymore.”

Or:

“I think we need to talk about goals of care.”

Or:

“We may be reaching a point where more treatment could cause more burden than benefit.”

You hear the words.

But your mind doesn't absorb them.

You look at the person you love.

They're still here.

Still breathing.

Still talking.

Maybe still laughing.

How can anyone talk about dying when they are sitting right there?

So you hold onto possibilities.

Sometimes because hope is real.

Sometimes because acceptance feels too much like betrayal.

If I accept that he may be dying, am I abandoning him?

If I stop pushing for treatment, am I causing this?

If I agree to hospice, does that mean I've given up?

These are painful questions.

But accepting reality does not cause reality.

Acknowledging that someone is dying does not make them die.

And choosing comfort when cure is no longer possible is not the absence of love.

It may be one of love's most difficult expressions.

Hope Doesn't Have to Disappear

We often imagine hope as only one thing:

Getting better.

But hope can change.

At first:

I hope the treatment works.

Later:

I hope we have more time.

Then perhaps:

I hope the pain can be controlled.

I hope she isn't afraid.

I hope he can stay at home.

I hope our children arrive in time.

I hope we can have one more conversation.

I hope she knows how much I love her.

I hope today is peaceful.

Hope can become smaller without becoming less meaningful.

Sometimes the smallest hopes become the most sacred ones.

A comfortable night.

A favorite song.

A few bites of ice cream.

A hand held.

A familiar voice.

A moment without pain.

A good day.

Hope does not have to die simply because its definition changes.

"Am I Doing Enough?"

Caregivers ask this constantly.

Especially near the end.

Should I be doing more?

Should I make them eat?

Should I get them out of bed?

Should we go back to the hospital?

Should I call the doctor again?

Should I wake them?

Should I push fluids?

Should I be talking to them?

Should I let them sleep?

Am I missing something?

What if I'm not doing enough?

Behind all those questions is love.

But sometimes there is also fear.

Because doing something gives us the illusion that perhaps we can control what is happening.

And there are moments in caregiving when there is very little left to control.

That's frightening.

Perhaps the question doesn't always have to be:

“Am I doing enough?”

Maybe sometimes it can become:

“What does this person need from me right now?”

Not tomorrow.

Not next week.

Right now.

Maybe the answer is medication.

Maybe it's a phone call.

Maybe it's repositioning.

But sometimes...

it's simply you.

Presence Is Still Doing Something

Sitting beside a bed can feel terribly inadequate.

Especially for someone who has spent months or years solving problems.

You sit.

They sleep.

You wait.

Nothing happens.

And your mind says:

I should be doing something.

But you are.

You are staying.

You are witnessing.

You are making sure someone is not alone.

You are creating safety.

You are holding a hand.

You are speaking softly.

You are allowing quiet.

You are being present.

Caregiving has taught you to measure usefulness by tasks.

But some moments cannot be improved by another task.

They can only be accompanied.

Presence is not what remains when there is nothing left to do.

Presence is something we do.

The Body Begins to Change

Near the end of life, families can become frightened by changes they don't understand.

The person may sleep more.

Eat less.

Drink less.

Become weaker.

Talk less.

Become confused.

Their breathing may change.

Their hands or feet may feel different.

And the caregiver who has spent months trying to maintain nutrition, hydration, mobility, and routine may feel as though they are failing.

He isn't eating.

She won't drink.

He's sleeping all day.

Something must be wrong.

Something is changing.

This is where good hospice and healthcare education can be such a gift.

Families need someone who can explain what they are seeing and what they should do.

Not with cold clinical language.

With gentleness.

With patience.

Sometimes repeatedly.

Because frightened people don't always remember the first explanation.

Knowledge cannot remove grief.

But it can reduce fear.

And caregivers deserve not to face unfamiliar changes alone.

You Cannot Love Someone Into Eating

Food is love in many families.

We cook.

Feed.

Bake.

Bring meals.

“Have you eaten?”

is almost another way of saying:

“I love you.”

So when someone nearing the end of life stops wanting food, caregivers can become deeply distressed.

“Just one bite.”

“Please eat something.”

“You need your strength.”

And underneath:

Please stay.

Sometimes the spoon carries much more than food.

It carries fear.

Hope.

Desperation.

Love.

When the body is changing, forcing normal routines may no longer accomplish what they once did. The healthcare team can help families understand what is appropriate for that person's condition.

But emotionally, the caregiver may need something else:

Permission to understand that declining appetite is not necessarily evidence that they have failed to care.

You fed them.

You nourished them.

You loved them.

And now love may look different.

The Last Job Is Not to Prevent Death

This may be one of the hardest sentences in the book.

For a long time, caregiving may have felt like keeping someone alive.

Watch the medications.

Prevent the fall.

Get them to the doctor.

Monitor the symptoms.

Call when something changes.

Encourage them to eat.

Protect them.

Then when someone is truly approaching the end of life, the caregiver's role may begin to shift.

You are no longer personally responsible for defeating death.

You never were.

But it can feel that way.

Your responsibility is not to somehow love perfectly enough that death cannot enter the room.

Your responsibility is to love the person who is in the room.

Those are different things.

You do not have to save someone in order to love them well.

"What If I Make the Wrong Decision?"

End-of-life caregiving can involve difficult decisions.

Hospital or home?

Another treatment or comfort-focused care?

Another test?

Another intervention?

Hospice?

Families can become terrified of making the wrong choice.

Sometimes siblings disagree.

Everyone loves the same person.

Everyone expresses that love differently.

One person says:

"Do everything."

Another says:

"Dad wouldn't want this."

One says:

"We can't give up."

Another says:

"We need to let him be comfortable."

These conflicts can become painful.

This is where conversations with physicians, nurses, hospice professionals, social workers, chaplains, and others can help.

But there is another question worth remembering:

What would the person we love say if they could clearly speak for themselves?

Not:

What makes us least guilty?

Not:

What will other relatives think?

But:

What mattered to them?

What did they value?

What would they consider an acceptable quality of life?

What did they tell us when things were different?

Sometimes love means speaking for someone when their own voice has become difficult to hear.

You May Never Feel Ready

Caregivers sometimes wait for a feeling called readiness.

I'll be ready when...

But how do you become ready to lose someone you love?

You may understand intellectually that death is approaching.

You may accept it spiritually.

You may even pray for peace.

And still think:

Not yet.

That doesn't mean you're in denial.

It means attachment is doing what attachment does.

Love reaches toward the person.

It wants another day.

Another morning.

Another conversation.

Another touch.

You do not have to become ready in order to walk through what is happening.

Sometimes we move through things while still wishing they weren't true.

Say the Things That Matter

If conversation is still possible, perhaps this is a time to simplify.

There are words that matter.

Thank you.

I'm sorry.

I forgive you.

I love you.

You have mattered to me.

We'll be okay.

You don't have to worry about us.

Sometimes there are complicated histories.

Not every relationship becomes beautifully resolved at the end of life.

Not every wound gets healed.

Not every family experiences a movie-scene goodbye.

That's okay.

Don't create another impossible standard.

Say what is true.

Say what is kind.

Say what needs saying if you can.

And if words aren't possible...

sit.

Hold a hand.

Play the music.

Read something meaningful.

Be there.

And Please Sleep

The caregiver may now become afraid to leave the bedside.

This connects to what we talked about earlier.

What if something happens while I'm sleeping?

What if I go shower?

What if I step outside?

What if I miss the moment?

So you watch.

Hour after hour.

Your body begins collapsing under vigilance.

Please remember:

You have already been present for thousands of moments.

If you need to sleep, sleep.

If you need to eat, eat.

If you need to shower, shower.

If someone trustworthy can sit while you rest, let them.

And if the person dies during a moment when you stepped away, please hear this:

You did not abandon them.

Death is not an appointment you failed to attend.

The love between you is larger than the final breath.

When Relief and Grief Arrive Together

Sometimes after a long illness, death brings an emotion caregivers are ashamed to admit.

Relief.

Then immediately:

How can I feel relieved?

Because you loved them.

Because you didn't want them to die.

But perhaps you also didn't want them to suffer anymore.

And perhaps you were exhausted.

There may have been years of caregiving.

Months without sleep.

Weeks of watching decline.

You can be devastated that someone died...

and relieved that suffering ended.

Again, we return to that little word from the last chapter:

And.

I am heartbroken.

And I am relieved.

I miss them terribly.

And I'm grateful they are no longer suffering.

I would give anything to have them back.

And I don't want them back in the condition they were in.

Grief contains contradictions.

You don't have to choose one feeling and reject the other.

Love Changes Jobs

Perhaps this is what happens near the end.

Love changes jobs.

For months, love may have been:

Schedule.

Manage.

Transport.

Feed.

Protect.

Treat.

Monitor.

Fix.

Then gradually love becomes:

Comfort.

Listen.

Reassure.

Remember.

Touch.

Forgive.

Release.

Stay.

And eventually...

grieve.

None of those forms of love is lesser.

The job changes.

The love remains.

A Presence Moment

Think about the person you are caring for.

For just a moment, set aside everything you are trying to fix.

The medications.

The appointments.

The decisions.

The equipment.

The symptoms.

Ask yourself:

What does love need to look like today?

Not yesterday.

Not what you thought caregiving would look like.

Today.

Perhaps love needs to make a phone call.

Perhaps love needs to ask for help.

Perhaps love needs to advocate.

Perhaps love needs to sit beside the bed.

Perhaps love needs to say something.

Perhaps love needs to become quiet.

Perhaps love needs to let someone sleep.

Perhaps love needs to let you sleep.

And maybe there is something you cannot fix.

Something you desperately wish you could change.

Name it quietly.

Then remind yourself:

My inability to fix this is not evidence that I have failed to love.

Again.

My inability to fix this is not evidence that I have failed to love.

You are not required to defeat illness.

You are not required to prevent every difficult moment.

You are not required to control death.

You are being asked to love a person through something neither of you chose.

And perhaps, at the end of all our doing, that is what presence has always meant.

Not fixing.

Not rescuing.

Not controlling.

Staying near.

There are two lives in this caregiving story.

And when one life can no longer be fixed...

both still deserve to be held with tenderness.

CHAPTER ELEVEN

The Caregiver Who Comes Home

What I See in My Husband

I married a man who spends a great deal of his life walking into rooms most people would rather avoid.

Rooms where someone is dying.

Rooms where a family has just received news they didn't want to hear.

Rooms where a husband is sitting beside the woman he has loved for fifty years and realizing he may soon have to live without her.

Rooms where daughters are trying to be strong.

Where sons don't know what to say.

Where grandchildren are frightened.

Where families are exhausted.

Where old wounds sometimes surface.

Where faith is questioned.

Where God sometimes feels very close.

And sometimes very far away.

My husband, Carlo, is a hospice chaplain and a bereavement chaplain.

I know there are many things he does in those roles.

But I don't see him primarily through the title.

I see him as his wife.

And I see something other people may not always see.

I see what happens to the caregiver after he comes home.

He Doesn't Just Visit Patients

People sometimes ask Carlo what he does.

The simple answer is:

He's a hospice chaplain.

But I've learned that the simple answer doesn't really explain it.

Because Carlo doesn't just visit patients.

He enters families.

He listens to stories.

He hears things people may not have told anyone else.

He sits with fear.

Regret.

Anger.

Questions.

Faith.

Doubt.

Unfinished relationships.

Sometimes he walks into a room where everyone is talking.

Sometimes he walks into a room where nobody knows what to say.

And he has to somehow understand the difference.

He cannot fix the disease.

He cannot stop death.

He cannot remove grief.

So much of what he does is what this entire book has been about.

He stays near.

I Can Hear It in His Voice

There are times Carlo talks about a patient or family and I can hear something different in his voice.

Maybe it was a husband caring for his wife.

Maybe a wife who hasn't slept.

Maybe children preparing to lose a parent.

Maybe someone who is frightened about dying.

Maybe there was reconciliation.

Maybe there wasn't.

Maybe something happened that was beautiful.

Maybe something happened that was heartbreaking.

I don't always need every detail.

Sometimes I can simply tell.

This one got to him.

There is a tenderness in Carlo that I love very much.

But tenderness means things can reach you.

And when your work requires you to remain open to people who are hurting, you don't simply turn that openness off because the workday ended.

He Notices the Person Beside the Bed

This is one of the things I have come to understand about my husband.

Carlo sees the patient.

Of course he does.

But he also notices the person sitting beside the patient.

The wife.

The husband.

The daughter.

The son.

The person who knows where every medication is.

The person who hasn't slept.

The person who says:

“I'm fine.”

The person everyone assumes is strong because they keep showing up.

I think that is one reason this book means so much to me.

Because I've watched Carlo care about those people too.

He understands something that families sometimes don't recognize until much later:

The person beside the bed is going through something too.

They may not have the diagnosis.

But their life has also been changed by it.

Sometimes He Comes Home Quiet

There are days when Carlo comes home and talks.

And there are days when he doesn't.

I've learned there are different kinds of silence.

There is ordinary silence.

Tired silence.

Thinking silence.

And then there is the silence that comes after you have spent a day standing close to something sacred and painful.

I don't always ask him to explain it.

Marriage teaches you when to ask:

“What happened?”

And when to simply be nearby.

Sometimes I think the person who spends all day being present for other people needs someone who can be present for him without requiring anything.

So sometimes I listen.

Sometimes we talk.

Sometimes we laugh.

Sometimes we eat.

Sometimes we sit.

Sometimes I simply let him come home.

He Carries Stories

Hospice workers learn things about people very quickly.

When time becomes precious, conversations can become different.

People talk about marriages.

Children.

Regrets.

God.

Forgiveness.

Fear.

Things they wish they had done.

Things they are proud of.

People they miss.

People they hope to see again.

And someone receives those stories.

The nurse receives some.

The aide receives some.

The social worker receives some.

The chaplain receives some.

Those stories are entrusted to them.

They are confidential.

They are sacred.

And even when the details cannot and should not be brought home, I think something of the encounter still comes home.

Not the private story.

The weight of having received it.

Then the Phone Rings

Hospice doesn't always respect dinner.

Or weekends.

Or quiet evenings.

Neither does grief.

Sometimes a family needs something.

Sometimes someone has died.

Sometimes a person Carlo has been following is suddenly gone.

Sometimes there is another grieving family.

And I watch him shift.

One moment he is my husband sitting at home.

Then the phone rings.

His voice changes.

He listens.

He becomes fully present to the person on the other end.

I've watched that happen enough times to recognize it.

And when the call ends, he returns to the room.

But perhaps not exactly the same as before the phone rang.

Because somebody else's grief just entered our evening for a little while.

Bereavement Doesn't End at the Death

This is another thing I've learned through Carlo.

People sometimes think hospice ends when the patient dies.

But grief has only begun.

There is a spouse waking up the next morning.

There is an empty chair.

A toothbrush.

Clothing in the closet.

Medication that is no longer needed.

A favorite cup.

A side of the bed nobody slept on last night.

There are children making arrangements.

Families notifying relatives.

People trying to understand what just happened.

And then eventually everyone else returns to their normal lives.

But the grieving person doesn't.

That is where Carlo's bereavement work continues.

He talks with families after the funeral.

After people stop bringing food.

After the cards stop arriving.

After everyone expects them to be “doing better.”

He knows grief doesn't operate according to everyone else's calendar.

I See What Caring Costs

This entire book has talked about the cost of caregiving.

The missed sleep.

The appointments.

The physical strain.

The emotional exhaustion.

The worry.

The constant vigilance.

Professional caregivers experience something different, but they are not immune to the cost of caring.

How could they be?

If you sit with suffering every day and nothing ever touches you, I'm not sure that's presence.

But if everything touches you and you never learn how to release anything, eventually the work can consume you.

There has to be a place between those two extremes.

Care deeply.

And come home.

Be present.

And rest.

Listen.

And allow yourself to become quiet again.

Hold other people's grief.

And remember that you cannot carry all of it forever.

I think Carlo continues learning that balance.

Maybe everyone who cares for people does.

The Chaplain Cannot Save Everyone Either

Chapter Ten talked about the painful realization that love cannot fix everything.

That applies to professional caregivers too.

A chaplain cannot heal every family conflict.

He cannot make someone believe.

He cannot erase regret.

He cannot reconcile people who refuse reconciliation.

He cannot remove fear from every dying person.

And he cannot somehow find the perfect words that make death acceptable.

Sometimes there aren't perfect words.

Perhaps that's why Carlo believes so deeply in presence.

Because there are moments when words become very small.

You sit down.

You listen.

You stay.

And maybe that's enough.

I Watch Him Give Away Something Invisible

This may be difficult to describe.

Carlo doesn't come home missing something you can see.

There isn't an empty bag.

There isn't a physical object he gave away.

But presence costs something.

Attention costs something.

Compassion costs something.

Listening costs something.

Entering someone else's suffering without trying to escape it costs something.

You give a little of your emotional energy.

Your concentration.

Your tenderness.

Your humanity.

One encounter may not seem like much.

But then there is another.

And another.

And another.

Over years.

That is why the people who care for caregivers also need care.

And Sometimes We Laugh

I don't want to make Carlo's work sound constantly heavy.

It isn't.

There is laughter too.

Families laugh.

Patients laugh.

Hospice workers laugh.

We laugh.

Sometimes laughter appears in the strangest places.

Maybe that's part of how human beings survive difficult things.

Death does not remove personality.

Illness doesn't eliminate humor.

Grief doesn't mean nobody is allowed to smile.

There can be tremendous sadness in a room...

and five minutes later somebody tells a story and everyone is laughing.

I think those moments matter.

They remind us that even near death, life is still present.

I Know the Man Who Comes Home

Families know Chaplain Carlo.

Coworkers know Carlo.

Patients know Carlo.

But I know my husband.

I know the man after the visit.

After the funeral.

After the difficult phone call.

After the long day.

I know when something is sitting with him.

I know when he needs conversation.

I know when he needs quiet.

I know when he needs to laugh.

And I know something else.

The tenderness that sometimes makes this work heavy for him is the same tenderness that makes him good at it.

I wouldn't want him to stop feeling.

I would just never want him to believe he has to carry everything he feels alone.

The Circle of Care

Writing this book has made me think about caregiving differently.

At first, it seemed simple.

There is the patient.

And there is the caregiver.

But now I see circles.

The patient needs care.

The family caregiver cares for the patient.

The nurse cares for both.

The aide helps.

The social worker supports the family.

The physician guides treatment.

The chaplain sits with questions and grief.

Friends bring food.

Neighbors help.

Someone stays with the caregiver so she can see her own doctor.

Someone listens to the nurse after a difficult day.

Someone loves the chaplain when he comes home.

Care moves outward.

And eventually it has to move back inward too.

Because no human being can endlessly give without receiving.

Who Cares for the Caregiver?

That question has followed us through this entire book.

Who cares for the caregiver?

Sometimes the answer is family.

Sometimes hospice.

Sometimes friends.

Sometimes a support group.

Sometimes a physician.

Sometimes a counselor.

Sometimes a chaplain.

Sometimes a spouse.

Sometimes several people together.

But perhaps the first step is simply noticing that the caregiver is there.

Look away from the hospital bed for a moment.

Look at the chair beside it.

Who is sitting there?

How long have they been sitting there?

When did they last sleep?

When did they last eat?

When did they last see their own doctor?

Who is listening to them?

Then widen the circle again.

Who is caring for the people who care professionally?

Who listens to the nurse?

Who checks on the aide?

Who gives the social worker room to breathe?

Who sits with the chaplain?

There are more than two lives in some rooms.

There is an entire circle of human beings trying to hold one another.

What I Want for My Husband

I want Carlo to keep being Carlo.

I want him to keep caring.

Listening.

Laughing.

Sitting beside people.

Offering hope.

Being quiet when quiet is what the moment needs.

I know this work matters to him.

And I know he matters to the people he serves.

But I also want him to come home.

Not simply physically.

I want him to come home to himself.

To rest.

To us.

To ordinary life.

To laughter.

To dinner.

To conversation.

To the things that have nothing whatsoever to do with hospice.

Because Carlo is a chaplain.

But he is not only a chaplain.

Just like the woman beside the hospital bed is a caregiver...

but she is not only a caregiver.

This book has asked caregivers to remember who they are beyond the care they provide.

I want that for my husband too.

Maybe This Is My Presence Moment

Every chapter has ended with a Presence Moment.

Maybe this one is mine.

So I'll turn toward the man I love.

Carlo,

I see you.

I see the people you carry in your heart.

I see how seriously you take the privilege of being invited into someone's most vulnerable moments.

I see the families.

I see the phone calls.

I see the funerals.

I see the grief.

I see the way someone's story can stay with you after you have left their home.

I see the joy too.

The laughter.

The relationships.

The strange beauty you sometimes find in places other people would expect only sadness.

And I see you when you come home.

I hope you always remember something you spend so much of your life reminding other people:

Your life matters too.

You don't have to carry every family home.

You don't have to have the perfect words.

You don't have to fix grief.

You don't have to save anyone.

You can love people.

Serve them.

Sit beside them.

And then you can come home.

I will be here.

Because perhaps even the person who spends his life offering presence...

needs someone waiting to offer presence to him.

And to every professional caregiver reading this—

the nurse,

the aide,

the social worker,

the physician,

the counselor,

the chaplain,

the bereavement professional,

and everyone else who repeatedly enters the suffering of another human being:

Please don't disappear inside your caring either.

The lesson we have offered family caregivers belongs to you too.

Keep your appointments.

Notice your exhaustion.

Talk to someone.

Rest.

Laugh.

Go home.

Let somebody love you.

There are patients who need you.

There are families who need you.

But there is also a life waiting for you beyond the room where someone is suffering.

Yours.

And that life deserves care too.

AFTERWORD

Before You Close This Book

A Final Word from Amy

When I first began thinking about this book, there was one thing I couldn't get out of my mind.

What happens to the caregiver?

We understandably focus so much attention on the person who is sick.

We ask about their medications.

Their appointments.

Their pain.

Their appetite.

Their sleep.

Their diagnosis.

Their prognosis.

Their comfort.

And we should.

They need our attention.

But somewhere nearby there is often another person.

The husband who has barely slept.

The wife who canceled her own doctor's appointment again.

The daughter trying to care for Mom while raising children and working.

The son who keeps telling everyone he's fine.

The granddaughter who suddenly finds herself doing things she never imagined she would have to do.

They don't have a hospital bracelet.

Nobody is checking their vital signs.

They may not have a chart.

But their life has changed too.

That's why I wanted to call this book The Other Patient.

Because sometimes, while everybody is watching the person who is sick, the caregiver's own health is quietly deteriorating.

And that frightens me.

I kept thinking about the caregiver who notices something isn't right with her own body but says:

“I'll deal with it later.”

The husband who has chest discomfort but doesn't want to leave his wife.

The daughter who is overdue for a physical but Mom has another appointment.

The caregiver who cancels a mammogram.

Postpones bloodwork.

Ignores exhaustion.

Stops exercising.

Doesn't sleep.

Eats whatever is convenient.

Keeps saying:

“After things settle down.”

But sometimes things don't settle down for months.

Or years.

And sometimes when they finally do, the caregiver discovers that something has been happening in their own body while they were busy taking care of someone else's.

I don't want that for you.

This book isn't asking you to care less.

Actually, I think it's asking you to understand care more completely.

Take care of the person you love.

Absolutely.

Hold their hand.

Make the meals.

Go to the appointments.

Ask the questions.

Sit beside the bed.

Advocate.

Comfort.

Laugh together.

Cry together.

Love them well.

But somewhere in all of that...

please don't lose yourself.

Keep your doctor's appointment.

Get the screening your healthcare provider recommends.

Refill your own prescription.

Tell someone when something hurts.

Tell your doctor you're a caregiver.

Sleep when you can.

Let somebody else sit beside the bed sometimes.

Go outside.

Eat.

Laugh.

Call a friend.

Ask for help.

And please don't wait until your body forces you to pay attention.

Writing the chapter about my husband made this even more personal for me.

I watch Carlo spend his days caring for people during some of the hardest moments of their lives.

As a hospice and bereavement chaplain, he listens.

He sits.

He comforts.

He laughs.

He cries.

He walks beside families through dying and then continues walking beside them through grief.

And because I love him, I want something for him that I want for every caregiver who reads this book.

Come home.

Not just to your house.

Come home to yourself.

Come back to the person you were before caregiving consumed the calendar.

Maybe that person has changed.

Of course you have.

Love changes us.

Loss changes us.

Caregiving changes us.

But you are still here.

And you still matter.

Maybe nobody has told you that recently.

So let me.

You matter.

Not because someone needs you.

Not because you remembered the medications.

Not because you stayed awake all night.

Not because you handled the emergency.

Not because you kept everyone together.

Not because you're strong.

You matter because you're a person.

And your life deserves the same tenderness you've been giving away.

Perhaps that's ultimately what I hope you remember from this book.

There really are two lives in every caregiving story.

The person receiving care.

And the person giving it.

Don't wait until the caregiver collapses before someone finally asks:

“How are you?”

Maybe we should start asking now.

And maybe if you're the caregiver reading this, you can begin by asking yourself.

How am I?

Really?

What have I been ignoring?

What do I need?

Who can help me?

When was the last time I saw my doctor?

What would caring for myself look like today?

You don't need to answer everything.

Just begin.

Because the person you love matters.

And so do you.

With love,

Amy Griseta

A Promise to Myself as a Caregiver

I will remember that there are two lives in this caregiving story.

I will care deeply without completely disappearing inside the care I provide.

I will keep my own medical appointments.

I will stay current with the screenings and healthcare my own medical providers recommend.

I will not continually dismiss symptoms because someone else is sicker than I am.

I will tell my healthcare provider that I am a caregiver and be honest about what caregiving is requiring of me.

I will remember that exhaustion is information, not something I always have to overcome.

I will ask for help before reaching complete exhaustion.

I will allow another trustworthy person to care for my loved one sometimes.

I will rest without believing that rest means I love less.

I will eat.

I will sleep.

I will step outside.

I will laugh when laughter comes.

I will cry when tears come.

I will maintain at least one connection to the world beyond caregiving.

I will tell someone when I am struggling.

I will remember that difficult feelings do not make me a bad caregiver.

I can say:

I love you, AND this is hard.

I will remember that I cannot fix everything.

I will remember:

My inability to fix this is not evidence that I have failed to love.

I will allow myself to be cared for too.

I will remember who I am beyond the tasks I perform.

And when caregiving changes or ends, I will give myself permission to discover who I am becoming.

The person I love matters.

And I matter too.

I will try not to disappear while loving you.

You Don't Have to Do This Alone

Caregiving can be beautiful.

It can also be exhausting, frightening, confusing, lonely, and overwhelming.

The Presence Network exists to help caregivers and families find compassionate support along the journey—including practical caregiving resources, emotional support and resilience, self-care and well-being resources, grief support, and encouragement rooted in compassionate presence.

Our resources are offered freely.

Because sometimes what a caregiver needs most is simply to know:

Someone sees me too.

The Presence Network

Presence is the quiet gift we offer when words are not enough.

www.thepresencenetwork.org