A WORKBOOK FOR CAREGIVERS WHO ARE SENIORS THEMSELVES

The Senior Caregiver's Workbook

Caring for an aging parent when you are no longer young yourself — your body, your money, your support, your limits, and your plan.

WHO THIS IS FOR

You are 62, or 70, or 78. Your parent is in their late eighties or nineties. Most caregiving advice assumes you are middle-aged, healthy, and employed. You are none of those things, and the standard advice does not fit.

This workbook is built for your situation specifically. Sixteen chapters, thirty-plus worksheets, and a 90-day plan you can actually follow.

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About this workbook

This is educational material, not professional advice. Nothing here is medical, legal, financial, or tax advice, and reading it does not create a therapist-client or advisor-client relationship. Every situation is different. Please work with your parent's physician and care team, a licensed elder law attorney in your state, a qualified financial professional, and — this part matters — your own doctor.

About the author. Esther Kane spent more than twelve years as an occupational therapist working with older adults, much of it inside their homes, watching families try to keep everyone safe with the resources they actually had. She holds the CAPS (Certified Aging-in-Place Specialist) and C.D.S. (Certified Dementia Specialist) designations and now writes full-time about aging in place and caregiving.

Find more at SeniorSafetyAdvice.com — including free checklists, articles, and the companion podcast for family caregivers.

A WORD BEFORE YOU START

This workbook asks you honest questions. Some of them will be uncomfortable — about your body, your money, your resentment, and what happens when you can no longer do this.

That discomfort is the point. The questions do not get easier by waiting, and every one of them is easier to answer now, at a kitchen table, than later, in a hallway outside an emergency room.

What's inside

HOW TO WORK THROUGH THIS

You do not have to go in order or do it all at once. If you only have energy for one thing, start with Chapter 3 — that is where the fastest, most permanent damage happens. If you are drowning emotionally, start with Chapter 14. The rest can wait a week.

1 The Caregiving Load Inventory

You cannot manage a load you have never measured. Caregiving grows quietly — an errand here, a phone call there — until one day it is a full-time job that nobody ever hired you for and you never agreed to.

Most caregivers underestimate their own hours by half. Fill this in for a typical week, and include the invisible work — the phone calls, the coordinating, the being on call.

Task	Hours/week	Who else could do this?
Personal care (bathing, dressing, toileting)		
Medication management		
Meals and food shopping		
Housekeeping and laundry		
Transportation and appointments		
Medical coordination and phone calls		
Insurance, bills, and paperwork		
Home maintenance and repairs		
Companionship and supervision		
Overnight or on-call time (and travel time)		

TOTAL HOURS PER WEEK **How many did you guess before?**

WHAT YOUR NUMBER MEANS

Under 10 hours: Sustainable for now. Use this window to build the systems in Chapters 8 through 12 *before* you need them.

10 to 20 hours: This is a substantial part-time job. Start delegating specific tasks now, not later.

21 to 40 hours: Full-time. Your health and finances are already being affected. Chapters 7 and 10 are urgent.

Over 40 hours: Beyond what one person of any age should carry alone. Read Chapter 15 this week.

1 The Caregiving Load Inventory — continued

Numbers only tell part of it. Rate each statement from 1 (never true) to 5 (constantly true).

Statement	1–5
I cancel my own plans because of caregiving	
I am the only one who knows how the whole system works	
I feel physically sore or exhausted after care days	
I lie awake thinking about my parent	
I have skipped my own medical appointments	
I feel resentment, then feel guilty about the resentment	
I cannot remember the last full day that was mine	
I worry about what happens if I get sick	
I have stopped seeing friends as often	
Money is tighter than it was two years ago	

TOTAL SCORE (out of 50) **Date completed**

A score above 30 is a caregiver who is running on reserve. A score above 40 is a caregiver heading for a health event of their own. Neither is a character flaw. Both are information.

Looking at the two pages you just filled in, what surprised you?

Which single task, if someone else took it over completely, would give you back the most life?

2 Your Own Health Audit

Here is the statistic that should change how you think about your role: more than half of family caregivers age 65 and older are living with two or more chronic health conditions of their own.

You are not a bystander who happens to be helping. You are a person with arthritis, or a heart condition, or a spine that has opinions — doing physical work that hospitals assign to trained staff with equipment. Your health is not a side issue. It is the infrastructure the whole care plan rests on, so let us audit it the same way we would audit your parent's.

My own conditions and limits

My condition	How it limits me physically	Getting better/worse?

Warning signs I have been explaining away

- [ ] New or worsening back, hip, knee, or shoulder pain
  Especially if it started or worsened after you took on care tasks
- [ ] Sleeping fewer than six hours most nights
- [ ] Weight change of more than ten pounds in either direction
- [ ] Blood pressure higher than it used to be
- [ ] Drinking more alcohol than a year ago
- [ ] Crying, snapping, or numbness that is new for me
- [ ] Chest tightness, shortness of breath, or dizziness on care days
- [ ] Skipping meals, or forgetting my own medications

IF YOU CHECKED THE FIRST BOX

New musculoskeletal pain in an older caregiver is rarely just aging. It is usually a specific mechanical task doing specific damage. Chapters 3 and 5 help you find which one. Please also tell your doctor you are doing hands-on caregiving — most caregivers never mention it, and their physician has no idea.

2 Your Own Health Audit — continued

Care I owe myself

Appointment or screening	Last done	Scheduled for
Annual physical / wellness visit		
Blood pressure check		
Bloodwork		
Dental cleaning		
Eye exam		
Hearing check		
Bone density / recommended screenings		
Specialist follow-up I have postponed		
Physical therapy I was referred to		
Mental health or counseling support		
Flu / other vaccinations		

Which one of these have I postponed the longest, and what have I been telling myself about why?

THE ONE COMMITMENT

Pick a single line from the table above and book it before you put this workbook down. Not after the next appointment of your parent's. Not when things calm down. Things do not calm down.

The appointment I am booking

The date I will call

3 The Two Fall Risks in Your House

When an older caregiver helps an older parent, there is not one fall risk in the room. There are two, and they are physically connected to each other.

Falls are the leading cause of injury for adults 65 and older, and about one in four reports a fall each year. Now put a 73-year-old with arthritic hands in the middle of that transfer.

THE DANGEROUS SENTENCE

“I can still lift her.”

Maybe you can. Once. On a good day, on a dry floor, when she does not panic halfway. But the day she buckles and you catch her, you both go down — and now you have a broken hip and she has no caregiver.

The question is never *can I do this today*. The question is *what happens the one time it goes wrong*.

Transfer-by-transfer risk assessment

For each transfer, mark how it actually goes — not how it goes on her best day.

Transfer	She does it alone	I steady her	I take her weight	Near-miss in last 6 mo?
Bed to standing				
Chair to standing				
On and off the toilet				
In and out of the tub or shower				
In and out of the car				
Up and down stairs or steps				
Off the floor after a fall				

Red flags — check any that are true

- ☐ I hold my breath or brace against a wall during a transfer
- ☐ I have felt a pull or twinge in my back doing this
- ☐ There has been a near-miss, or I have thought “we got lucky”
- ☐ She has fallen and I could not get her up without help
- ☐ I do transfers when I am tired, or at night

3 The Two Fall Risks — continued

IF YOU CHECKED ANY BOX ON THE PREVIOUS PAGE

That transfer needs to change — not through more effort or better technique, but through equipment, a second person, or a different approach entirely. Everything in Chapters 4 and 5 exists to get your body out of the middle of it.

Which single transfer worries me the most, and why?

What would have to be true for that transfer to stop being dangerous? (Equipment? A second person? A different room? A different living arrangement?)

THE PHONE CALL WORTH MAKING

Ask your parent's physician for a referral for an **occupational therapy home safety evaluation**. If your parent has a qualifying need, Medicare often covers occupational therapy delivered in the home.

An OT will watch the actual transfer, in the actual room, and recommend the specific equipment that removes your body from the risk. They will find in twenty minutes what you have walked past for two years — and a physician's recommendation is often what makes equipment coverable.

Doctor I will ask

Date I will call

4 Equipment Instead of Effort

This is the single most important rule in this workbook, and it is four words long.

> **Equipment instead of effort.**
>
> Every time your body is the safety device, you are one bad second away from being a patient instead of a caregiver.

There is context worth knowing here: only about ten percent of American homes have the basic features that make them usable for someone with mobility limits. If the house feels like it is fighting you — it is. It was not built for this.

Walk through the house with this workbook in hand. Check what is already there. Circle what is missing. Then use the planning table at the end of the chapter.

THE BATHROOM — where most of the danger lives

- [ ] Grab bars by the toilet, anchored into studs or with approved anchors
  Not a suction cup. Not the towel bar. Towel bars fail under load.
- [ ] Grab bars in the tub or shower, positioned for how she actually moves
- [ ] Shower chair or bench, with rubber feet in good condition
- [ ] Transfer bench if she has to step over a tub wall
- [ ] Handheld shower head so nobody is standing and reaching
- [ ] Non-slip surface in the tub and a non-slip mat outside it
- [ ] Raised toilet seat or a toilet safety frame
- [ ] Bedside commode available for night use
- [ ] Lever-style faucet handles instead of round knobs
- [ ] Door that opens outward, or can be removed in an emergency
- [ ] Night lighting bright enough to see the floor

THE BEDROOM

- [ ] Bed at a height where her feet touch the floor when seated
- [ ] Bed rail, half-rail, or a sturdy anchored assist bar
- [ ] Hospital bed if sitting up has become a struggle
- [ ] Clear, lit path from bed to bathroom — no rugs, no cords
- [ ] Lamp or light switch reachable from the bed
- [ ] Phone and water within reach without standing

4 Equipment Instead of Effort — continued

STAIRS, ENTRIES, AND GETTING IN AND OUT

- [ ] Handrails on both sides of every staircase, inside and out
- [ ] Handrails that extend past the top and bottom step
- [ ] Contrast marking on the edge of each step
- [ ] A threshold ramp where there is a step at the door
- [ ] Stairlift, or a workable plan for one-floor living
- [ ] Outdoor lighting on the path, driveway, and entry
- [ ] A place to set groceries down while unlocking the door

KITCHEN AND LIVING AREAS

- [ ] Everyday items between waist and shoulder height — no step stools
- [ ] A sturdy chair with arms she can push up from
- [ ] Chair or sofa at a height that does not require a pull-up
- [ ] Clear walking paths at least 32 inches wide
- [ ] Cords secured, throw rugs removed or taped down
- [ ] Stove with an automatic shutoff, or a plan for supervision
- [ ] Smoke and carbon monoxide alarms tested in the last six months

THROUGHOUT

- [ ] Lighting increased everywhere — older eyes need far more of it
- [ ] Motion-sensor night lights along the route to the bathroom
- [ ] Medical alert device that works outside the house too
- [ ] Emergency numbers posted large enough to read without glasses
- [ ] A working plan for what happens in a power outage

4 Equipment Instead of Effort — your fix list

Do not try to do all of it. Rank by risk, not by cost or convenience. As a rule, fix in this order: the bathroom first, then the path from the bed to the bathroom, then stairs and entries, then everything else.

What needs to change	Room	Cost estimate	By when	Done

PAYING FOR IT

Before you buy retail, check all of these: durable medical equipment may be partly covered by Medicare with a physician's order; your Area Agency on Aging may run a home modification or minor repair program; some states have Medicaid waivers that fund modifications; veterans may qualify for VA home adaptation grants; and local Habitat for Humanity affiliates and civic groups sometimes install grab bars and ramps at low or no cost.

Also worth knowing: a used shower chair or transfer bench from a medical resale shop or a senior center loan closet is often a fraction of retail and works exactly as well.

The one change that would make the biggest difference to my safety — and the date I will have it done by:

5 Body Rules for Caregivers Over Sixty

If a transfer cannot be avoided today, these rules reduce the odds that it costs you something permanent. They are not a substitute for equipment. They are what you do while the equipment is on order.

1. Never lift what you can slide.

Sliding, sitting, pivoting, and scooting are all safer than lifting. A slide board, a draw sheet, or a swivel cushion beats your lower back every single time.

2. Never try to catch a falling person.

You will not win, and you will both go down. If someone is going down, your job is to protect their head and guide them toward the floor — not to reverse gravity.

3. Get close before you move anything.

Weight held away from your body multiplies the load on your spine. Get chest to chest. Get the wheelchair right up against the bed.

4. Set the scene first, every time.

Lock the brakes. Move the footrests. Clear the path. Put shoes on her feet. Most transfer injuries happen because of something in the room, not something in the lift.

5. Count out loud.

“Ready, one, two, three, stand.” Uncoordinated effort is what causes buckling. She needs to know exactly when it is happening.

6. Never do a hard transfer when you are tired, rushed, or angry.

Late at night, after a long day, in a hurry to get somewhere — that is when it goes wrong. Wait five minutes. Sit her back down.

7. Use a gait belt, and learn how properly.

Never pull on an arm, a shoulder, or clothing. Ask a physical or occupational therapist to teach you — twenty minutes of real instruction is worth more than any video.

8. If it takes two people, it takes two people.

Not one person and determination. If she has fallen and is uninjured, many fire departments will do a free non-emergency lift assist. Call and ask what yours does.

IF SHE FALLS AND YOU ARE ALONE

Do not pull her up. Check for injury and for pain, especially at the hip. If anything seems wrong, or if she cannot help at all, call for help. If she is uninjured and able to assist, the safe method is a gradual roll to hands and knees, then to a sturdy chair brought alongside — with you coaching, not lifting. Ask a therapist to walk you both through it once, before you need it.

5 Body Rules — your own plan

The three moments in a normal week when my body is most at risk:

For each one — what equipment, person, or change would remove me from the middle of it?

What is stopping me from making that change? (Cost? Her resistance? Not knowing where to start? Pride?)

ON HER RESISTANCE

Many older parents refuse equipment because it feels like an admission. A grab bar means she is old. A shower chair means she is failing.

The reframe that tends to work is not about her at all: *"Mom, I need this for me. My back cannot do it the old way anymore, and if I get hurt, I cannot help you at all."* That is true, it is not a guilt trip, and it moves the conversation off her decline and onto a shared problem.

6 What This Is Actually Costing You

Family caregivers spend an average of roughly $7,200 a year out of pocket. That is an inconvenience at 45, when you can pick up more hours. At 72, on a fixed income, it is a different thing entirely.

You cannot work more to cover this. That option is gone. So the money comes out of savings, or the emergency fund, or the roof you were going to replace. You are not just spending money — you are spending your own future care.

Track one honest month. Most people are shocked.

Expense	This month	Notes
Groceries and food for her		
Medications and copays		
Medical supplies (pads, wipes, wound care)		
Equipment and home modifications		
Paid help / home care hours		
Adult day program		
Transportation, gas, parking		
Her household bills I cover		
Her insurance premiums		
Home repairs at her house		
Travel to see her		
Meals out because I had no time to cook		
Things I bought to make my life bearable		

MONTHLY TOTAL

Annual projection (× 12)

6 What This Is Costing You — the harder math

Out-of-pocket spending is only the visible layer. Fill in what you can.

The invisible costs	My estimate
Retirement savings drawn down this year	
Income lost (part-time work, consulting, rental)	
Social Security claimed earlier than planned	
Home maintenance of my own deferred	
My own medical care deferred	
Trips or plans cancelled	
Debt taken on	

If this continues at the current rate for three more years, where does that leave me financially?

What is my personal line — the amount or the point at which I would have to change the arrangement?

BEFORE YOU SPEND DOWN YOUR OWN SAVINGS

Talk to an elder law attorney — before, not after. Money you spend on your parent's care from your own accounts is generally gone, and it may complicate her eligibility for benefits later while doing nothing to protect you. One consultation can change the entire financial shape of the next five years. Chapter 7 covers what may be available.

7 Benefits and Programs Worth Checking

Most families discover these years late, or never. Almost all of them are free to ask about. Work down this list and log what you learn.

Your Area Agency on Aging

Every county has one. They are the front door to respite care, meal delivery, transportation, senior center programs, and caregiver support. Find yours through the Eldercare Locator: 1-800-677-1116 or eldercare.acl.gov.

National Family Caregiver Support Program

Federally funded, delivered locally through the Area Agency on Aging. Can include respite hours, counseling, training, and in some places supplemental funds for supplies or equipment.

Medicare home health and therapy

If your parent qualifies, Medicare may cover skilled nursing, physical therapy, and occupational therapy in the home, plus some durable medical equipment. Requires a physician's order — which is why Chapter 3 asks you to make that call.

Medicaid and Home and Community-Based Services waivers

Rules vary widely by state. Waiver programs can fund in-home care, and in a number of states a family member can be paid to provide it. Ask your Area Agency on Aging or an elder law attorney what your state offers.

PACE — Programs of All-Inclusive Care for the Elderly

Where available, PACE bundles medical care, day programs, therapy, and transportation for people who qualify for nursing home level of care but want to stay home. It is one of the most underused options in the country.

VA Aid and Attendance

For qualifying wartime veterans and surviving spouses who need help with daily activities. It is a monthly benefit added to a VA pension. The VA also runs caregiver support programs and respite.

Adult day programs

Often the highest-value respite per dollar: structured days, meals, activities, and supervision. Costs vary widely, and some are subsidized.

Tax and employer angles

Your parent may qualify as a dependent, and some medical expenses you pay may be deductible. Ask a tax professional — the rules are specific and worth getting right.

7 Benefits — your call log

Ask three questions on every call: *What do you offer? What does my parent have to qualify for it? What is the very next step?* Write down the name of the person you spoke with — it matters when you call back.

Who I called	Date	What they said	Next step / by when

IF YOU HIT A WALL

Being told “you do not qualify” on the phone is not always the final answer. Ask specifically which program you were screened against, ask whether a different program has different criteria, and ask whether there is an appeal. Persistence is unglamorous and it works.

8 Mapping Who Is Actually Available

At 45, your support bench is deep. At 72, it has quietly emptied out — and nobody announced it.

One sibling has passed. One had a stroke. Your best friend from church moved to be near her own kids. Your spouse may need care himself. The people who would normally rotate in have aged out, so the load does not get shared. It concentrates. On you.

Name names. Vague resources do not show up when you are in the hospital.

Name	Relationship	What they realistically could do	Asked yet?

Who used to help and no longer can? (Naming this out loud matters — it is a real loss, and it explains why this feels harder than it did three years ago.)

Who have I never asked because I assumed the answer would be no?

9 How to Ask So People Say Yes

“Let me know if you need anything” is not an offer, and “I could use some help” is not a request. Both of them fail for the same reason: neither one contains a task.

People — especially far-away siblings — usually are not refusing. They are waiting for something specific enough to say yes to. A good ask has four parts.

A specific task. Not “help with Mom.” Rather: drive her to the Thursday cardiology appointment.

A specific date or window. “The second Saturday of each month” beats “sometime.”

A defined end. “For the next three months” makes it possible to say yes. Open-ended requests feel like a life sentence.

A graceful exit. “If that does not work, tell me and I will ask someone else” removes the pressure that makes people avoid you.

Scripts you can borrow

TO A DISTANT SIBLING

“I need to talk about Mom, and I am not asking you to move home. Here is what would actually help: could you take over her insurance paperwork and prescription refills? It is mostly phone and computer work, and you can do it from there. I will send you the account details this week.”

TO A NEIGHBOR OR CHURCH FRIEND

“Would you be willing to sit with Mom for two hours on Wednesday afternoons so I can get to my own doctor? She mostly watches her programs. If Wednesdays are hard, any afternoon works.”

TO YOUR OWN ADULT CHILDREN

“I am 71 and I am doing this mostly alone, and I need you to know that. I am not asking you to take over. I am asking for one specific thing: could you handle Grandma's grocery order every week from your phone?”

9 How to Ask — your three asks

Write three real asks. Real names, real tasks, real dates. Then make them within two weeks.

ASK #1

Who I am asking

By when I will ask

The specific task, date, and duration

ASK #2

Who I am asking

By when I will ask

The specific task, date, and duration

ASK #3

Who I am asking

By when I will ask

The specific task, date, and duration

WHEN THE ANSWER IS NO

Some people will say no, and some will say yes and then not follow through. That is real, and it hurts. It is also information: that person is not on the bench, and you can stop spending energy hoping they will be. Move to the next name and, if the bench is genuinely empty, move to paid help — which is Chapter 10.

10 Building a Respite Plan That Is Real

Respite is not a reward for coping well. It is maintenance on the only piece of equipment in this system that cannot be replaced.

Almost everyone treats respite as something that happens when there is a gap. There is never a gap. It has to be scheduled like a cardiology appointment, because it is the same category of thing.

Your respite ladder — from smallest to largest

Level	What it looks like	Who or where	Cost	Have I set it up?
2 hours				
Half a day				
A full day				
An overnight				
A week away				

Sources worth investigating

- [ ] Area Agency on Aging respite hours (often free or subsidized)
- [ ] Adult day program — half or full days
- [ ] Home care agency — even four hours a week on a standing schedule
- [ ] Faith community volunteer or visitor program
- [ ] Short-stay respite at an assisted living or nursing facility
- [ ] Hospice respite benefit, if your parent is enrolled in hospice
- [ ] A family member who takes one predictable, recurring block

My first respite date — in ink

What I will do with it

THE HONEST WARNING

The first time you take real respite, you may feel guilty, restless, or strangely flat rather than relieved. That is normal and it passes by about the third time. Do not judge the whole idea by the first afternoon.

11 The Documents That Have to Exist

These can only be signed while your parent still has the capacity to understand them. That window closes without warning — a stroke, a bad UTI, a fast slide in a dementia. There is no later guaranteed.

Document	Exists?	Where kept	Who has a copy	Needs updating?
Durable POA — financial				
Healthcare POA / proxy				
Advance directive / living will				
POLST or DNR, if appropriate				
HIPAA release naming me				
HIPAA release naming my backup				
Will or trust				
Deed, lease, or title				
Insurance policies				
Long-term care policy				
Military DD-214				
Account inventory				
Funeral or burial wishes				

And the same list for yourself

You need every one of these documents too, and most caregivers have never made them. If you are hospitalized, someone has to be able to act for you — and for your parent, through you.

My healthcare proxy is

My financial POA is

Where my documents are kept

Last updated

12 Your Own Backup Plan

The question almost nobody asks in time: if I were hospitalized tomorrow, what happens to my parent in the next twenty-four hours?

If you cannot answer that with a name and a phone number, that is your emergency — more urgent than anything on your parent's chart.

My primary backup caregiver **Phone**

My second backup **Phone**

Has the handoff actually been built?

- [ ] Backup person has agreed out loud — not been assumed
- [ ] Backup person has a key or the door code
- [ ] Backup person is named on a signed HIPAA release at the doctor's office
- [ ] A written one-page handoff sheet exists
- [ ] Copies of that sheet are in her home and in my backup's hands
- [ ] My backup knows about the medications, the transfers, and the routine
- [ ] My backup knows which behaviors mean “call the doctor”
- [ ] I have photographed every page of it on my phone
- [ ] It is on my calendar to review in six months

THE COMPANION CHECKLIST

The full one-page handoff sheet — medications, care team, daily routine, equipment, documents, and your own information — is available free at **SeniorSafetyAdvice.com** as *The “If I Go Down” Emergency Backup Plan*. Print it, fill it in by hand, and give a copy to one other human being. It takes about 45 minutes and it is the single highest-value hour in this entire workbook.

If I could not care for my parent starting tomorrow morning, what would be the first thing to fall apart?

13 Naming What You Have Given Up

A younger caregiver tells herself: I will travel later, I will rest later. Later exists.

When you are 71 and your mother is 96 and reasonably healthy, “later” might be five more years. Maybe eight. And those are your good years — the ones where you can still hike, still drive at night, still get on a plane without it being a production.

That is a real loss. Not a selfish one. A real one. You are allowed to grieve it while still showing up every day, and doing both at once does not make you a hypocrite. It makes you a person.

What did I think my sixties and seventies would look like?

What have I said no to in the last two years because of caregiving?

What have I quietly stopped doing without ever deciding to?

What is one thing from that list I want back — even in a smaller version?

TWO GRIEFS AT ONCE

You are grieving your parent while she is still alive — that is anticipatory grief, and it is well recognized. But you are also grieving your own last good decade. That second grief almost never gets named, which is why it so often comes out sideways as irritability, numbness, or a resentment you cannot explain. Naming it does not fix it. It does make it recognizable, and recognizable is much easier to carry.

14 Guilt Is Not the Same as Responsibility

Guilt is the feeling that you have done something wrong. Most caregivers carry enormous guilt in situations where nothing wrong has occurred.

You feel guilty for being tired. For being short with her. For wanting a weekend. For the thought that flickers through at 3 a.m. and horrifies you. None of that is wrongdoing. It is the nervous system of a human being under sustained load.

Responsibility is different. It is finite, it can be shared, and it can be delegated. Guilt is infinite and takes everything you feed it. Telling them apart is what keeps you deciding based on what is actually safe rather than on what quiets the feeling fastest.

The guilt audit

The guilty thought	Did I actually do something wrong?	What is truly mine to carry?

What am I holding myself to a standard for that I would never hold a friend to?

WHAT YOU MAY NEED TO HEAR

You are allowed to make a decision that is not purely heroic.

If the transfers have become unsafe, that is information — not a moral failure. If paid help costs money, that money is buying two people's safety, not one. If it is time to talk about assisted living or memory care, that conversation is an act of love, not a betrayal.

Loving your mother at 94 does not require you to injure yourself at 72. It never did.

15 Deciding in Advance When the Plan Changes

The worst decisions in caregiving are made in hospital corridors at eleven at night, by exhausted people with no time. The way out of that is to decide the thresholds now, while you are calm.

This is the same principle behind an advance directive, applied to you. You are writing down, in advance, what conditions would mean the current arrangement has to change — so that when one of them happens, you are following a decision you already made rather than making one in a crisis.

Common thresholds worth setting

- [ ] She has fallen and I could not get her up
- [ ] I have been injured doing a transfer
- [ ] She needs help more than once during the night, most nights
- [ ] She has left the house alone and become disoriented
- [ ] She can no longer be safely left alone for the time I need
- [ ] A stove, a bathtub, or a car has become genuinely dangerous
- [ ] My own health has measurably declined
- [ ] We are spending down savings faster than a set amount per month
- [ ] Incontinence care has become more than I can manage
- [ ] She no longer recognizes me, or becomes fearful of me

Which of these is closest to being true right now?

15 When the Plan Changes — writing it down

Now put it in your own words, specific enough that you would recognise the moment when it arrives. “If _____ happens, then we will _____ within _____.”

If this happens...	...then we will do this	Within

WHY WRITING IT DOWN WORKS

A threshold you set while calm is a decision made by the version of you with the most information and the least panic. When the moment arrives, you are not deciding under pressure — you are following through on something you already thought carefully about. Share these with your siblings, and with your parent if she is able to take part.

15 When the Plan Changes — preparing the ground

Deciding is one thing. Being able to act is another. These are the pieces that determine whether you can move when a threshold is crossed.

Groundwork to lay now

- [ ] Tour two or three facilities before you need one
  Waiting lists are real, and touring under pressure leads to bad choices. Go once. Take notes. Put the folder somewhere you can find it.
- [ ] Find out what each one actually costs, and what level of care it covers
  Ask specifically what happens when needs increase and what triggers a price change.
- [ ] Ask an elder law attorney what your parent would qualify for
  Do this before spending down. The answer often changes the plan.
- [ ] Talk with your siblings before the crisis, not during it
  Even a difficult conversation now is easier than a decision made by three exhausted people over speakerphone.
- [ ] Ask your parent what she would want, while she can still say
  “If you ever needed more help than I can give, what would matter most to you?” Ask it once, early, and write the answer down.
- [ ] Write down her answer, with the date
  It will matter enormously later — both practically and for your own peace.

What my parent said she would want, and when she said it

A CHANGE IS NOT AN ENDING

Moving your parent to assisted living or memory care does not end your role. It changes it — from doing the physical work to overseeing the care, advocating, visiting, and being her daughter or son again instead of her lifting equipment. For many families that shift is the thing that gives the relationship back.

16 Your 90-Day Plan

Pull everything forward into one page per month. Small, specific, dated. Three real things per month beats thirty aspirations.

DAYS 1–30 — Safety and the emergency layer

Suggested focus: the bathroom, the riskiest transfer, the backup person, and one appointment for yourself.

What I will do	By when	Done

DAYS 31–60 — Support and money

Suggested focus: the Area Agency on Aging call, three specific asks, the first respite date, and the cost tracker.

What I will do	By when	Done

DAYS 61–90 — Documents and the long view

Suggested focus: the paperwork gaps, the elder law consultation, your written thresholds, and one facility tour.

What I will do	By when	Done

16 Your 90-Day Plan — the review

Put a date on the calendar ninety days from today to come back to this page. Then answer these three questions honestly.

Today's date

My review date

What actually changed?

What did I not do, and what was really in the way?

Am I in better shape — physically, financially, emotionally — than I was ninety days ago? If not, what has to change now?

THE MEASURE THAT MATTERS

The goal was never to carry this until you break. The goal is to still be standing — for her, and for whatever comes next in your own life. Every honest answer on this page serves both of those.

Resources and where to call

Eldercare Locator — 1-800-677-1116 · eldercare.acl.gov
The national front door to local aging services. One call gets you your Area Agency on Aging, which is the gateway to nearly everything else.

National Family Caregiver Support Program — Through your Area Agency on Aging
Respite, counseling, training, and in some areas supplemental funds.

Medicare — 1-800-633-4227 · medicare.gov
Coverage questions, home health, durable medical equipment, and the care compare tools for agencies and facilities.

VA Caregiver Support Line — 1-855-260-3274 · caregiver.va.gov
Aid and Attendance, caregiver programs, and respite for veterans' families.

PACE program locator — npaonline.org
Find out whether a Program of All-Inclusive Care for the Elderly operates in your area.

Alzheimer's Association Helpline — 1-800-272-3900, 24 hours
Free, staffed around the clock, and useful for any dementia — not only Alzheimer's.

National Academy of Elder Law Attorneys — naela.org
Find a qualified elder law attorney in your state.

988 Suicide and Crisis Lifeline — Call or text 988
If the weight of this ever becomes more than you can hold, this line is for you too — not only for emergencies.

One last thing

If you have worked through even half of this workbook, you have done something most caregivers never do: you looked directly at the parts that are frightening, and you wrote them down anyway.

That is not a small thing. It is the difference between being carried along by this and steering it.

Take care of yourself. I mean that literally.

Esther Kane, CAPS, C.D.S.

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