



A WORKBOOK FOR FAMILY CAREGIVERS

# Is It Time?

The Caregiver's Workbook for Moving Your  
Person with Dementia to a Community

- The capacity truth: why this was never about love running out
- The home safety walk through and red flag checklist
- Assisted living, memory care, home care, adult day, and hospice decoded
- The exact questions to ask on every tour
- Worksheets to score communities and plan the money

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READ THIS FIRST

# Moving Them Is Not Failing Them

Let's deal with the guilt first, because I know it's sitting on your chest right now.

You promised you'd never put them in a home. You said you could handle it. And now you're holding a workbook about moving them, and part of you feels like a traitor.

**Hear me: moving them is not failing them.**

You are not abandoning your person. You are changing where their care happens. That's it. You will still be their advocate, their voice, their family. You're trading the job of exhausted caregiver for the job you were always meant to have: being their person.

Guilt is not proof you're doing the wrong thing. Guilt is proof you love them. Those are two different things, and this workbook will help you tell them apart.

If you're their child, this is the strangest role reversal of your life. You're parenting your parent, and nobody handed you a manual. If you're their spouse, you made vows, and moving them can feel like breaking them. It isn't. 'In sickness and in health' never specified an address. Love doesn't live at an address. It lives in how well they're cared for.

I've spent more than 20 years in dementia care. I've been the family caregiver. I've been the professional. I've owned and operated a memory care community. I have sat with hundreds of families in this exact moment, and here's what I learned: the families who waited too long didn't wait because their person was safe at home. They waited because of guilt.

**Let's not let that be your story.**

## How to use this workbook

Go at your own pace. One page today, one page next week, that counts. The worksheets are where the clarity happens, but there's no deadline and no grade. We can only do what we can do, and right now, you're doing it.

**You're not failing them. You're fighting for them. This is hard, but we can do hard things. Let's figure out the next right step together.**

**Joanna**

# The Capacity Truth

**The number one reason families move their person with dementia to a community is not love running out. It's capacity running out.**

Every human has a capacity. Think of it as a cup. Your cup holds your sleep, your health, your job, your family, your bills, and now the growing needs of your person with dementia.

Dementia care is not a fixed pour. It grows. The disease progresses, the needs multiply, and the cup that handled everything last year is overflowing this year. You didn't shrink. The pour got bigger.

And here's what happens when you keep pouring past capacity: you get sick. Your body keeps score even when you refuse to. Caregivers who run past empty end up with their own health crises, and then there are two patients instead of one.

## The question that changes everything

If you go down, who takes care of both of you?

Needing help is not weakness. It's math. A cup can only hold what it can hold. When your person's needs grow bigger than your capacity, the answer isn't to become a bigger cup. The answer is more cups: a community, more hands, trained staff around the clock.

You can be a devoted daughter, son, husband, or wife and still be out of capacity. Both things are true at the same time. One does not cancel the other.

## Say it back to yourself

Choosing a community is not quitting the team. It's changing your position so you can stay in the game. Let trained staff carry the bathing, the meds, and the 3am wakeups so you can carry the love.

# Your Capacity Check

Rate each area honestly. Not how it looked last year. How it is right now. There are no wrong answers here, just true ones. Circle one number per row: 1 means running on empty, 5 means solid.

My sleep

1 2 3 4 5

My physical health

1 2 3 4 5

My mental health

1 2 3 4 5

My patience with my person

1 2 3 4 5

My finances

1 2 3 4 5

My job or career

1 2 3 4 5

My other relationships: family and friends

1 2 3 4 5

My backup: people who can actually step in

1 2 3 4 5

**My total: \_\_\_\_\_ out of 40**

**The area that scares me most right now:**

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**What I've stopped doing for myself since caregiving started:**

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## What Your Score Means

### 33 to 40: You have capacity today.

Use this workbook to plan ahead so a crisis never makes this decision for you. The best moves are planned, not panicked.

### 24 to 32: Your cup is filling fast.

Start touring communities now. Not because the move is tomorrow, but because waitlists are real and decisions made mid crisis are the worst decisions you'll ever make.

### 15 to 23: You are past capacity.

Your health is already paying for this, whether you've noticed or not. It's time, and you don't have to figure it out alone. That's what the rest of this book is for.

### 8 to 14: This is a flashing red light.

You are the second patient now. Moving your person is not one option among many. It's the plan, and you've already started on it just by being here. Use this workbook to do it well.

#### Before the guilt talks

A score is not a grade. A low number doesn't mean you failed. It means you're human and the job got bigger than one human. That's not a character flaw. That's dementia. Whatever your number, you're allowed to ask for help carrying it.

**My score:**

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**What my score is telling me:**

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**Who I will tell about my score this week:**

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# The Safety Red Flags

**Capacity is reason one. Safety is reason two. And safety doesn't negotiate.**

These questions are hard to read, and harder to answer. Ask them anyway. You can handle the truth better than you can handle a 2am phone call:

- **Fire.** If a fire started, could your person get out on their own? Would they understand the alarm, or would they hide from it? People with dementia often hide from alarms instead of leaving.
- **The door.** If a stranger knocked and meant harm, would your person let them in? Many people with dementia will open the door to anyone with a friendly face.
- **The stove.** Burners left on. Kettles boiled dry. Food forgotten in the oven. This is one of the most common calls I get from terrified families.
- **Wandering.** Leaving the house at 2am in January. Getting lost on a street they've lived on for 30 years. It only takes once.
- **Medications.** Doubling doses because they forgot they took them. Skipping the pills that keep their heart beating.
- **Falls.** Lying on the floor for hours because no one was there to help them up.

## The line in the sand

One of these alone might be manageable with home changes. Two or more, and home may already be the most dangerous place your person can be.

## One more truth

A locked door and a camera can't supervise. Supervision means a human, awake, paying attention, around the clock. If that human is only you, go back to the capacity chapter.

# The Home Safety Walk Through

Walk through your person's home this week with this page in hand. Check every box that's true. Be honest, even when it stings. This part is hard, and you can do it anyway.

- ☐ My person could not get out alone in a fire
- ☐ My person would open the door to a stranger
- ☐ The stove or oven has been left on in the past 6 months
- ☐ My person has wandered or tried to leave the house confused
- ☐ Medications are missed, doubled, or unsupervised for part of the day
- ☐ My person has fallen when no one was there
- ☐ My person is alone for hours at a time
- ☐ My person can no longer use a phone to call for help
- ☐ Food in the fridge is expired, or my person is losing weight
- ☐ Bills go unpaid, money goes missing, or scam calls are getting through
- ☐ Hygiene is slipping: same clothes for days, bathing battles, accidents
- ☐ Neighbors or family have called me because they're worried

**Boxes I checked:** \_\_\_\_\_

**0 to 2 boxes:** Watch and plan. Recheck this list every 3 months. Dementia doesn't stand still.

**3 to 5 boxes:** Home is getting risky. Increase support now and start touring communities.

**6 or more:** Safety has already made the decision. Your job is to act on it this month, with the pages ahead and the people around you. Not alone.

## Who Licenses What

**You have more options than you think. Here they are, and here's who's watching each one. Because who oversees the care matters more than the chandelier in the lobby.**

- **Long term care (skilled nursing).** The most regulated setting in senior care. Overseen by the federal government (CMS) plus your state, with regular surveys. Inspection results are public on Medicare's Care Compare website.
- **Assisted living.** Licensed by your state. No federal oversight. The rules, the inspections, and even the name vary state to state.
- **Memory care.** Usually licensed as assisted living with extra state requirements like secured doors and dementia training. Some states require almost nothing extra. Ask what the word means where you live.
- **Skilled home care.** Medicare certified agencies are regulated and surveyed under CMS rules.
- **Private duty home care.** In many states there is no license, no survey, and no one checking on them at all. Michigan, for example, has no licensing for these companies. Anyone can open one tomorrow.
- **Adult day programs.** Varies by state. Some license them, some certify them, some don't touch them.
- **Hospice.** Medicare certified and regulated under federal rules, with public inspection results on Medicare's Care Compare website. Quality still varies, so you choose the provider.

### Check your state in 4 moves

1. Search your state plus 'assisted living licensing' and look for the official state agency site, where inspection reports are often public. 2. Look up any nursing home or hospice on Medicare's Care Compare site. 3. Call your local Area Agency on Aging. Free help, every county has one. 4. Your state's long term care ombudsman is free, independent, and on your side.

## OPTION 1

# Assisted Living

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### WHAT IT IS

Housing plus help with daily living: medications, bathing, dressing, meals, housekeeping. A social setting with support, not a medical facility.

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### WHO IT FITS

Your person needs help and supervision through the day but not around the clock nursing. Early to mid stage dementia can fit here, with eyes wide open about what comes next.

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### STAFFING

Aides in the building around the clock. Nurse availability varies wildly from building to building. Ask exactly which hours a nurse is on site.

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### WATCH FOR

Secured memory care does not come standard. If your person wanders or their needs grow, a general assisted living can ask them to move. Ask up front: what would make you discharge my person?

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### WHO PAYS

Mostly private pay. Long term care insurance if you have it. Some states have Medicaid waivers with waitlists. VA Aid and Attendance can help veterans and surviving spouses.

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### BALLPARK COST

National median runs around \$6,000 per month and climbs every year. Your zip code decides. Care levels and medication management often cost extra on top of base rent.

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#### Joanna's tip

Ask every community for the full fee schedule in writing, including care level pricing. The base rate on the brochure is almost never the real monthly number.

## OPTION 2

# Memory Care

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### WHAT IT IS

Assisted living built for dementia: secured doors, smaller spaces, staff trained in dementia communication, and activities designed for the disease instead of around it.

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### WHO IT FITS

Wandering risk. Exit seeking. Challenges that overwhelm a general assisted living. Mid to late stage dementia. If safety brought you to this book, you're probably shopping here.

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### STAFFING

Should be higher staff ratios than assisted living and dementia specific training. The word 'should' is doing real work in that sentence. Verify everything.

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### WATCH FOR

In some states, 'memory care' is a marketing word with no legal teeth. Ask what training staff actually get, how many hours, and how often it's refreshed. Vague answers are an answer.

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### WHO PAYS

Same sources as assisted living: private pay, long term care insurance, Medicaid waivers in some states, VA benefits for those who qualify.

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### BALLPARK COST

National median lands around \$8,000 per month. The real range runs \$6,000 to \$12,000 depending on your market, and high cost areas can hit \$18,000.

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#### Joanna's tip

On your tour, watch the residents instead of the decor. Are they engaged or parked? Do staff greet them by name? The hallway tells you more than the sales office ever will.

### OPTION 3

## Long Term Care (Skilled Nursing)

### WHAT IT IS

Around the clock nursing care for medical needs beyond what assisted living or memory care can handle: feeding tubes, wound care, two person transfers, complex conditions.

### WHO IT FITS

Late stage dementia with heavy medical needs, or your person's body needs more than aides can legally provide.

### OVERSIGHT

Regulated by CMS and your state, surveyed regularly, with public inspection reports on Medicare's Care Compare website. Read them before you tour.

### WHO PAYS

Medicaid is the main payer for long stays. Medicare only covers short rehab stays after a hospital admission, up to 100 days, and rarely the full 100. Private pay and some long term care insurance fill the gaps.

### BALLPARK COST

Private pay runs \$9,500 to \$11,500+ per month nationally, and far higher in some states. This is where Medicaid planning becomes everything.

#### Joanna's tip

Talk to an elder law attorney early, even if a nursing home feels far away. Medicaid planning done years ahead can protect your family's savings. Done in a crisis, it mostly can't.

## OPTION 4

# Home Care Decoded

Two completely different services share the name 'home care.' Families mix them up every day, and it costs them. Here's the difference.

|                          | Skilled Home Care                                                                                            | Private Duty Home Care                                                                                     |
|--------------------------|--------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------|
| <b>What it is</b>        | Nurses plus physical, occupational, and speech therapy. Ordered by a doctor. The goal is rehab and recovery. | Hands on help: bathing, meals, companionship, supervision. No doctor's order needed.                       |
| <b>Who regulates</b>     | CMS, if Medicare certified. Surveyed regularly.                                                              | Varies by state. In many states, no one. No license, no surveys.                                           |
| <b>The staff</b>         | Licensed professionals: RNs, therapists, certified aides. Background checks required.                        | No license required in many states. Background checks and drug tests are not guaranteed. Ask for proof.    |
| <b>How long it lasts</b> | Until your person stops progressing toward goals. Often 6 to 8 weeks.                                        | As long as you keep paying.                                                                                |
| <b>What it costs</b>     | Medicare often covers it in full. Other insurance can carry a copay.                                         | Roughly \$30 to \$40 per hour nationally. Around the clock care runs about \$25,000 per month, often more. |

### The math nobody runs

Around the clock home care costs about \$25,000 a month. That's roughly triple the median memory care bill. Families assume home is the affordable option. The math says otherwise. Run your real numbers on the cost worksheet at the back of this book.

## OPTION 5

# Adult Day: The Most Underused Tool in Dementia Care

Adult day programs give your person supervision, meals, activities, and people. They give you 6 to 8 hours to work, sleep, go to your own doctor, or remember who you are.

### Use it three ways:

- **A capacity extender.** Adult day can add months or even years to how long home works, because it refills your cup a few days a week.
- **A test run.** Watch how your person does with group activities, new faces, and a routine outside the house. It's a preview of community life with a return ticket.
- **A bridge.** Use it while you tour communities and sit on waitlists, so the next move is planned instead of panicked.

What it costs: roughly \$100 per day nationally. Some Medicaid waivers and VA programs cover it. Hour for hour, it's still the most affordable paid dementia care that exists.

### The script that gets them in the door

If the word 'daycare' makes you cringe, never say it to your person. Call it the club. Call it volunteering. Call it lunch with friends. Your person doesn't need the brochure title. They need the day.

### Joanna's tip

Try saying: 'They need your help down at the center on Tuesday. You always know how to get people talking.' Purpose works better than persuasion. Every time.

# Is It Time for Hospice?

**Hospice is not giving up. It's giving your person comfort, dignity, and a team, in the season when cure is no longer the goal. And families almost always wish they had called sooner.**

Dementia is a terminal disease. Most families don't realize their person can qualify for hospice, and they miss months of support they were entitled to. Here are the signs that the late stage has arrived.

- **Weight loss.** Losing weight without trying, often 10 percent or more in 6 months, or eating far less than they used to.
- **Few or no words.** Speech has dropped to a handful of words a day, sometimes a single word, sometimes none.
- **Mostly bed or wheelchair.** They can no longer walk on their own and need full help to move.
- **Trouble swallowing.** Coughing or choking on food and drink, or food pocketing in the cheeks. This raises the risk of pneumonia.
- **Repeated infections.** Recurring pneumonia, urinary tract infections, or fevers that keep coming back even after antibiotics.
- **Full help with everything.** Bathing, dressing, eating, and toileting all require another person. Incontinence is constant.
- **Skin breakdown and falls.** Pressure sores that won't heal, or frequent falls.

## The one question to ask the doctor

Doctors use a tool called the FAST scale. When your person reaches stage 7, needing help to walk, with limited words and full care needs, plus one of the signs above, they often qualify for hospice under Medicare. You don't have to score this yourself. Just ask the doctor: do you think my person could be hospice eligible?

## What Hospice Is and Why It Helps

Hospice is a team that comes to your person, wherever they live: your home, an assisted living, a memory care, or a nursing home. The goal shifts from fixing to comfort, and from your shoulders to a whole team's.

### WHAT THE TEAM BRINGS

- **A nurse.** Regular visits to manage pain, agitation, and symptoms, plus a number you can call 24/7.
- **Aides.** Hands on help with bathing and personal care, the exact tasks that wear caregivers down.
- **A doctor and medications.** Comfort focused medicines, delivered to the door, covered by the benefit.
- **Equipment and supplies.** Hospital bed, wheelchair, briefs, and more, brought to you at no extra cost.
- **A social worker and chaplain.** Support for the hard conversations, the paperwork, and the spirit, for your person and for you.
- **Volunteers and extras.** Many hospices offer volunteers to sit with your person, plus ancillary services like massage, music, and pet therapy. These can be so soothing for someone with dementia. Always ask what's offered and how often your person can receive it.

### What it costs

For people with a qualifying diagnosis, the Medicare hospice benefit covers the team, the visits, the medications related to the illness, and the equipment. Most families pay little to nothing. You do not have to be wealthy to get this care.

### Two myths, busted

Choosing hospice doesn't mean death is days away. Many people live months on hospice, and some get better and graduate off it. And here's the part nobody tells you: it also covers grief support for your family for a full year after.

## Finding a Dementia Educated Hospice

**Not all hospices are equal, and very few are truly skilled with dementia. You can choose your hospice. You are never stuck with the one the hospital names first. Ask these questions before you sign.**

- ☐ 1. Are you Medicare certified, and what did your last inspection find?
- ☐ 2. How is your staff trained specifically in dementia, not just general hospice care?
- ☐ 3. Will my person have the same nurse and the same aide every visit? A person with dementia cannot handle a new face every week.
- ☐ 4. How do you keep that consistent when someone calls off? What is your backup plan so my person isn't meeting a stranger?
- ☐ 5. How often will the nurse visit, and will it be the same day and time every week so we can count on it?
- ☐ 6. Do you offer volunteers or extras like massage, music, or pet therapy? If so, how often can my person receive them?
- ☐ 7. How fast do you respond to an after hours call? Who shows up, a nurse or a phone line?
- ☐ 8. How do you manage agitation and pain in someone who can't tell you where it hurts?
- ☐ 9. Who owns this hospice, and why did they start it? Listen for a real story, not a sales pitch.
- ☐ 10. Can I talk to two current families as references?

### Why consistency matters

Consistency is everything in dementia care. The same two faces, on a schedule your person can feel even if they can't say it, lowers agitation and builds trust. The extras like music and pet therapy are the cherry on top. Ask for all of it.

# Tour Questions: Assisted Living and Memory Care

Print one copy per tour. Check the box as you ask. A good community answers all of these without flinching. Part one: the care.

- ☐ 1. What is your staff to resident ratio on days? On nights? On weekends? Then the follow up: does that number count hands on caregivers only? Supervisors, dietary, and activities staff don't provide care. They don't count.
- ☐ 2. What dementia training does your staff get? Follow up: is it completed before they ever work a shift, or do they learn on my person? Is it in person or just a video? How many hours, and how often is it refreshed?
- ☐ 3. Which dementia expert or method is your training built on? A real program has a name behind it. 'We do our own training' is not an answer.
- ☐ 4. Is a nurse in the building or on call? Which hours, exactly?
- ☐ 5. What happens when my person's needs increase? What would make you ask us to leave? Get it in writing.
- ☐ 6. How do you handle challenges like refusing care, exit seeking, or sundowning? Listen for approach and redirection, not medication first.
- ☐ 7. Who creates the care plan, how often is it updated, and am I at the table?
- ☐ 8. How do you tell families about falls, incidents, and changes? How fast?
- ☐ 9. What happened here yesterday? Ask to see the activity calendar, then ask which activities actually ran.

## Don't let them slide

The ratio question is the one communities dodge most. If the answer is 'it depends on acuity' with no number attached, ask again. And when they finally give you a number, make sure it counts the people with their hands on residents, not everyone with a badge.

## Tour Questions: Part Two, Money and Gut Check

- ☐ 10. Can I see your most recent state inspection report? They should hand it over without blinking.
- ☐ 11. What's included in the base rate, and what costs extra? Ask for the full fee schedule in writing.
- ☐ 12. How much has your monthly rate increased in each of the last 3 years?
- ☐ 13. What's the move in fee, and is any of it refundable?
- ☐ 14. Can I visit anytime, unannounced?
- ☐ 15. How long has your executive director been here? Your care director? Turnover at the top means turnover everywhere.
- ☐ 16. Can I talk to two current families as references?

### Notes from this tour:

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#### Red flags that end the tour

Walk away if they discourage unannounced visits. If residents are parked with nothing to do. If the hallways smell like urine. If staff walk past residents without a word. Or if they pressure you to sign today for a 'special rate.' A good community never needs a hard sell.

BRING THIS WITH YOU

## Questions for Home Care Agencies

For private duty agencies especially, you are the inspector. In many states, nobody else is checking. Ask every one of these.

- ☐ 1. Are you bonded and insured?
- ☐ 2. Are your caregivers your employees or contractors? Employees mean more accountability.
- ☐ 3. Are background checks, drug tests, and driving record checks required? Ask to see proof, not a promise.
- ☐ 4. What training do caregivers get? Video or in person? How many hours?
- ☐ 5. Are your caregivers trained in dementia specifically? Ask for an example of how they'd handle a tough moment.
- ☐ 6. Who do I call after hours when something goes wrong?
- ☐ 7. Do caregivers check in and out electronically so I know they showed up?
- ☐ 8. What happens if my caregiver doesn't show? How often are you unable to staff a shift?
- ☐ 9. Will we get the same caregiver consistently, or a rotating cast of strangers?
- ☐ 10. Why did the owner start this company? Does anyone in leadership have a medical background?
- ☐ 11. Do your caregivers plan real activities with my person, or turn on the TV and scroll their phone? Ask for an example.

### The question that tells you everything

That last question separates the great agencies from the babysitters. Real engagement, things your person can still do and feel proud of, is the whole point of one to one care.

BRING THIS WITH YOU

## Questions for Adult Day Programs

Visit during program hours, not before they open. You want to see the room running.

- ☐ 1. Are you licensed or certified in this state? By whom?
- ☐ 2. What is your staff to participant ratio?
- ☐ 3. What dementia training does your staff have?
- ☐ 4. Is a nurse on site? Can you give medications during the day?
- ☐ 5. What does a typical day look like? Can we do a trial day before we commit?
- ☐ 6. How do you handle wandering or exit seeking?
- ☐ 7. What happens if my person refuses to participate or gets distressed?
- ☐ 8. Do you provide transportation? Meals? At what cost?
- ☐ 9. What is the daily rate, what's extra, and do you offer half days?
- ☐ 10. How will you tell me how the day went?

### The 10 minute test

Watch the staff during your visit. Are they sitting with participants or standing in a corner talking to each other? You'll know in 10 minutes.

### WORKSHEET 3

# The Community Scoresheet

Tour at least 3 communities, even if you fall in love with the first one. Score each from 1 to 5 after every tour, while it's fresh. Highest total wins, unless your gut says otherwise. Your gut gets a row too.

| Score each from 1 to 5<br>Write each community's name: | Community A<br>_____ | Community B<br>_____ | Community C<br>_____ |
|--------------------------------------------------------|----------------------|----------------------|----------------------|
| First impression: clean, bright, smells right          |                      |                      |                      |
| Staff greeted residents by name                        |                      |                      |                      |
| Residents engaged, not parked in front of a TV         |                      |                      |                      |
| Clear answers on staffing ratios                       |                      |                      |                      |
| Real dementia training, with hours and details         |                      |                      |                      |
| Inspection report: clean, and handed over freely       |                      |                      |                      |
| Costs transparent and in writing                       |                      |                      |                      |
| Activities calendar matched what I saw happening       |                      |                      |                      |
| Distance from me: I can visit often                    |                      |                      |                      |
| My gut feeling walking out the door                    |                      |                      |                      |
| <b>TOTAL (out of 50)</b>                               |                      |                      |                      |

### The tiebreaker

Tied scores? Go with the building where the staff looked your person in the eye. Decor fades. People are the care.

## WORKSHEET 4

# The Money Worksheet

Fear of the cost keeps families frozen. Real numbers unfreeze them. So take a breath, fill in what you actually have, then compare it to what each option actually costs. They're just numbers, and numbers can be worked with.

### WHAT WE HAVE EACH MONTH

My person's income (Social Security, pension):

\_\_\_\_\_

Savings we could put toward care monthly:

\_\_\_\_\_

Long term care insurance benefit:

\_\_\_\_\_

VA benefits (Aid and Attendance, if eligible):

\_\_\_\_\_

Family contributions:

\_\_\_\_\_

Home equity (sale or rental of the house):

\_\_\_\_\_

**Total available per month: \$** \_\_\_\_\_

### WHAT EACH OPTION COSTS

**Option 1:** name: \_\_\_\_\_ monthly cost: \$ \_\_\_\_\_

**Option 2:** name: \_\_\_\_\_ monthly cost: \$ \_\_\_\_\_

**Option 3:** name: \_\_\_\_\_ monthly cost: \$ \_\_\_\_\_

#### Do this before you sign anything

Talk to an elder law attorney before you spend down savings. Medicaid planning done early can protect years of money. Done late, it mostly can't. One consult now can save your family tens of thousands.

#### Run all three

Compare apples to apples. Around the clock home care vs memory care vs adult day plus part time help. Most families have never put the three numbers side by side. The answer usually surprises them.

## What to Say When It's Time

**You will not win a debate with dementia, and you don't need to. Your job is to lower the fear, not deliver a truth they can't hold onto. The trick is simple: make it you and your person on the same team, against an outside problem. Never you against them.**

Build a fib that blames something outside both of you. The house needs major repairs. The pipes, the wiring, the heat, something that has to be fixed before anyone can stay there safely. Then you get to stand beside them, frustrated at the same thing they are. You become teammates waiting on the contractors, not opponents fighting over a move.

And when they ask to go home? You blame the contractors. 'They're still working on it. You know how slow they are.' The problem stays outside. You stay on their side.

**Instead of:** *You have dementia and you can't live alone anymore, so you're moving to memory care.*

**Try:** **The house has a big plumbing problem and it isn't safe to stay there while they fix it. We found a great place to stay in the meantime.**

**Instead of:** *This is your new home now. You live here.*

**Try:** **We're staying here until the repairs are done. You and me, we'll just wait it out together.**

**Instead of:** *You can't go home, stop asking.*

**Try:** **I called the contractors again. Still not ready, you know how they are. As soon as it's safe, we'll talk.**

### One story, everyone tells it

Whatever fib you choose, write it down and give it to everyone: family, friends, and the care team. One story, told the same way, every time. Mixed answers create panic. One calm, consistent reason is a gift.

## Getting Them to Accept Help at Home

A stranger in the house can feel like an insult to a proud person: 'I don't need a babysitter.' So don't frame it as help for them. Same rule as before. You and your person on one team, the reason coming from outside. Here are three fibs that work.

- **Make it help for you, not them.** 'She's here to help me with the house and the cooking. I've been so swamped. You'd be doing me a favor letting her get things done.' Now accepting help is them being generous, not them being needy.
- **Make them the mentor.** 'These are nursing students who need hours to finish their training. They just need someone to practice with. You'd be helping them out.' A person with dementia loves having a purpose. Give them one.
- **Make it a free perk.** 'The insurance sends someone a few days a week, it's already paid for, so we may as well use it. No sense wasting it.' Free and practical is easy to say yes to.

### Ease them in

Introduce the caregiver as a friend or a helper, never as 'your caregiver.' Have them visit short the first few times, share a coffee, do one small task, then leave. Trust gets built in tiny doses, not all at once.

### Why this isn't lying

None of this is lying to be cruel. It's meeting your person in the reality they live in now, the one where logic doesn't land but feeling safe still does. A kind fib that keeps them calm beats a hard truth that steals their peace.

# The Guilt Doesn't Stop, and That's Normal

Nobody warns you that the hardest part can come after the move. The 'take me home' calls. The empty house. The voice in your head asking if you did the right thing. You did. Here's how to get through the part nobody talks about.

- **Expect a rough two weeks.** The adjustment period is real and it's temporary. Most people settle once a routine forms. Give it time before you judge whether it's working.
- **The 'take me home' calls will gut you.** Home often means a feeling, not an address: safe, young, in charge. You can't deliver that house, but you can deliver the feeling. Redirect to comfort and a visit, then let the staff help them settle.
- **Step back so staff can step in.** If you're there every hour, your person may never bond with the team. Hard as it is, a little space helps them build new trust.
- **Become the advocate, not the aide.** Your new job is watching the care, asking the questions, and catching what slips. That's not less love. That's a different, powerful kind.

## The goodbye that breaks your heart

Time your visit to end right before a meal or an activity. Walk your person there, get them settled with food or people, then leave with a reason that makes sense in their world: 'I've got to make dinner for the kids,' 'I have to get to church,' 'I have class.' Then add: 'I'm headed there now, but I'll see you very soon.' You're not sneaking out. You're handing them off to something good and giving them a reason they can accept.

## The truth to hold onto

You did not abandon them. You found them more care than two hands could give. On the hard nights, read that again.

# The All About Me Care Plan

**No one will ever know your person the way you do. But you can hand a brand new caregiver a head start. Fill out the next two pages, then give a copy to whoever is caring for your person: home care, an adult day program, hospice, or a community.**

Staff can't ask your person who they are anymore. So they ask this page. It tells them the career your person was proud of, the music that calms them, the words that set them off, and how to reach them on a hard day. It turns a stranger into someone who walks in already knowing your person.

## HOW TO USE IT

- **Make copies.** Give one to every caregiver, aide, and nurse who works with your person. The more hands, the more copies.
- **Keep it visible.** Tape it inside a closet door or post it in their room. New staff and fill-ins should be able to find it fast.
- **Update it as things change.** Dementia doesn't stand still. When a routine, a comfort, or a trigger shifts, mark it up and hand out a fresh copy.

### Why it matters

This one page can prevent so many hard moments. A caregiver who knows your dad was a firefighter, hates being rushed, and settles with Elvis is a caregiver who can actually reach him. That's the difference between care and connection.

### Your move

Print the next two pages. Fill them in with your person if they're able, or on your own if they're not. Then hand them to the people who will love your person when you can't be in the room.

# ALL ABOUT ME

A guide to my preferences, routines, and care

NAME

I prefer to be called

Important people in my life

Former career and meaningful life roles

Typical daily routine

Activities I enjoy

Music I enjoy

Topics I like discussing

Comfort items that help me feel secure

What may cause anxiety

# ALL ABOUT ME

A guide to my preferences, routines, and care

NAME

Signs that I am becoming overwhelmed

Helpful ways to approach me

Words or approaches to avoid

What helps redirect me

Mobility needs and fall risks

Eating and drinking preferences

Bathroom routine

Bedtime routine

What others should know about my current situation

YOU'VE GOT THIS

## Your Next Steps

### THIS WEEK

- ☐ Take the Capacity Check on page 4. Write the real numbers.
- ☐ Do the Home Safety Walk Through on page 7.
- ☐ Tell one person the truth about how you're actually doing.

### THIS MONTH: PICK THE PATH THAT FITS

- ☐ Not ready to move yet? Set up adult day or home care to extend how long home works, using the question sheets on pages 16 and 17.
- ☐ Looking at a move? Tour at least 3 communities with the question sheets and the scoresheet.
- ☐ Late stage or heavy medical needs? Ask the doctor if your person qualifies for hospice, then use the hospice questions on page 16.
- ☐ Call your local Area Agency on Aging and ask what help exists in your county. Free, every county has one.
- ☐ Run the real numbers on the Money Worksheet so you're comparing facts, not fears.
- ☐ Talk to an elder law attorney about Medicaid planning.

#### Read this on the hard days

You are not failing them. You are fighting for them. This is hard, but we can do hard things. Whatever path you choose, you are still their person, and that never changes.



### About Joanna

Joanna LaFleur, BS, TRS, has spent more than 20 years in dementia care as a family caregiver, a professional, and the owner and operator of a memory care community. She's the author of *Bringing Joy Every Day: A Year of Dementia Friendly Activities*, and she teaches family caregivers around the world how to handle the hard moments with skill instead of guilt.

#### Keep learning with me:

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