



New Caregiver

FAMILY CARE TOOLKIT

Choosing Care

Decision guides for families

Plain-language comparisons, the questions to ask, and the red flags to watch for when you are weighing home care, assisted living, memory care or a PACE program.

WE ARE CHOOSING CARE FOR

NAME

DECISION NEEDED BY (DATE)

WHO IS HELPING DECIDE

STARTED ON

Inside: Needs check · Care options at a glance · Who pays for what · Home care guide · Assisted living guide · Memory care guide · PACE guide · Visit scorecard · Cost comparison · Family decision meeting · Where to get help

START HERE

How to use these guides

There is rarely one right answer, and the best choice can change as needs change. These guides help you narrow the options, ask sharper questions, and compare places on the same terms instead of on first impressions.

1

Get clear on needs

Use the Needs Check (page 3) with everyone who sees your person day to day. Ask their doctor for input too.

2

Narrow the options

Care Options at a Glance (page 4) and Who Pays (page 5) show which types of care fit those needs and your budget.

3

Ask the right questions

Each guide has the questions to ask by phone and on a visit, plus red flags. Check them off as you go.

4

Compare side by side

Score up to three options on the Visit Scorecard (page 14) and total real monthly costs on page 15.

5

Decide together

Use the Family Decision Meeting page to agree on a choice, a backup plan and who does what next.

Include your person in the decision

As far as they are able, the person receiving care should help choose it. People adjust better to a move or new helpers when their preferences shaped the choice. Ask what matters most to them: staying home, being near family, privacy, a pet, faith community, the food, a garden. Write it on the Family Decision Meeting page and use it as a tiebreaker.

When it's urgent: if a hospital or rehab discharge is forcing a fast decision, ask to speak with the case manager or social worker the same day. Ask which places have openings, whether a short-term stay is possible while you decide, and how long you have. A temporary choice is fine. You can keep comparing.

This guide is general information, not medical, legal or financial advice. Licensing rules, program names and coverage differ by state and by insurance plan. Confirm details with each provider and your plan.

STEP 1

Needs Check

Mark the level of help needed today. Be honest. Families often underestimate needs because they are already quietly filling the gaps.

DAILY PERSONAL CARE	DOES IT ALONE	SOME HELP	FULL HELP
Bathing or showering	☐	☐	☐
Dressing	☐	☐	☐
Eating	☐	☐	☐
Using the toilet / continence	☐	☐	☐
Getting in and out of bed or a chair	☐	☐	☐
Walking or getting around safely	☐	☐	☐

RUNNING A HOUSEHOLD	DOES IT ALONE	SOME HELP	FULL HELP
Taking medications correctly	☐	☐	☐
Cooking and nutrition	☐	☐	☐
Managing money and bills	☐	☐	☐
Driving or getting to appointments	☐	☐	☐
Housework and laundry	☐	☐	☐
Using the phone / staying in touch	☐	☐	☐

SAFETY & HEALTH	DOES IT ALONE	SOME HELP	FULL HELP
Falls (any in the last 6 months?)	☐	☐	☐
Memory, confusion or getting lost	☐	☐	☐
Wandering or leaving home unsafely	☐	☐	☐
Being alone at night	☐	☐	☐
Skilled care (wounds, injections, oxygen, tube feeding)	☐	☐	☐
Loneliness or isolation	☐	☐	☐

What your answers suggest

- **Mostly 'some help' with household tasks:** part-time home care, adult day programs, meal and ride services.
- **Personal care help several times a day:** more hours of home care, assisted living, or PACE if eligible.
- **Memory loss with wandering, unsafe exits or not safe alone:** memory care, 24-hour supervision at home, or PACE.
- **Daily skilled nursing needs:** home health (short term), skilled nursing, or PACE. Ask the doctor.

STEP 2

Care Options at a Glance

The main types of long-term care, what each one is for, and when it tends to fit.

TYPE OF CARE	WHAT IT IS	USUALLY A GOOD FIT WHEN
Home care non-medical	Aides come to the home for companionship, errands, meals, bathing, dressing and supervision. Hourly, up to 24/7.	They want to stay home, the home is safe or can be made safe, and needs are predictable.
Home health	Short-term skilled care at home ordered by a doctor: nursing, physical, occupational or speech therapy.	Recovering from a hospital stay, surgery or a new diagnosis. Not ongoing daily help.
Adult day program	Supervised daytime program with meals, activities and sometimes health services. Some specialize in dementia.	They live with family who work or need a break, and they would benefit from structure and social time.
Assisted living	Residential community with an apartment, meals, activities and help with personal care and medications. Staff on site 24/7.	They need daily help and oversight but not continuous nursing, and isolation or home upkeep is a problem.
Memory care	Secured residence or wing with staff trained in dementia care, structured days and closer supervision.	Dementia is causing wandering, unsafe exits, distress, or needs beyond what home or assisted living can manage.
PACE Program of All-Inclusive Care for the Elderly	A Medicare and Medicaid program that coordinates all medical care and long-term services through one team and a day center, while the person lives at home.	They are 55+, live in a PACE service area, are certified by the state as needing nursing-home-level care, and can live safely at home with support.
Skilled nursing nursing home	Licensed nursing care around the clock, short-term rehab or long-term care.	Medical needs require nurses 24/7, or rehab after a hospital stay.
Hospice	Comfort-focused care for a serious illness, delivered wherever the person lives, with support for the family.	A doctor expects six months or less if the illness runs its usual course, and the focus has shifted to comfort.

STEP 2

Who Pays for What

The most common surprise for families: Medicare does not pay for long-term custodial care, meaning ongoing help with daily activities. Use this as a starting map, then confirm with each plan.

TYPE OF CARE	MEDICARE	MEDICAID	OTHER COMMON SOURCES
Home care	Generally no, unless part of a Medicare Advantage plan's extra benefits (limited).	In many states, through home and community-based services or waiver programs. Waitlists are common.	Private pay, long-term care insurance, VA benefits.
Home health	Yes, when a doctor certifies the need and the person is homebound. Part-time and intermittent.	Yes, in all states.	Private insurance, Medicare Advantage plans.
Adult day	Generally no.	Often through state waiver programs.	Private pay, VA, long-term care insurance.
Assisted living	No for room and board or personal care.	Some states help pay for services (not room and board) through waivers.	Mostly private pay; long-term care insurance; VA Aid and Attendance.
Memory care	No for room and board or personal care.	Same as assisted living; varies widely by state.	Mostly private pay; long-term care insurance; VA.
PACE	Yes. PACE is a Medicare and Medicaid program.	Yes. People with Medicaid usually pay no monthly premium.	Medicare-only enrollees pay a monthly premium for the long-term care portion, plus Part D. Some programs accept private pay.
Skilled nursing	Short-term skilled care after a qualifying hospital stay, for a limited number of days with a daily copay after day 20.	Yes, for long-term care once financially eligible.	Private pay, long-term care insurance.
Hospice	Yes, under the Medicare hospice benefit.	Yes.	Most private insurance.

Get free, unbiased help with coverage

- **SHIP (State Health Insurance Assistance Program):** free Medicare counseling in every state.
- **Your Area Agency on Aging:** local programs, waiver applications and benefits screening. Find yours through the Eldercare Locator.
- **An elder law attorney:** before spending down assets or transferring property for Medicaid. Medicaid has look-back rules.

GUIDE 1

Home Care

Home care can mean a few hours a week or round-the-clock help. Most families hire through an agency, a registry, or directly. Each comes with different responsibilities.

HOW YOU HIRE	WHO EMPLOYS THE AIDE	WHAT TO KNOW
Home care agency	The agency	Handles screening, payroll, taxes, insurance, supervision and backup when an aide is out. Typically the highest hourly rate.
Registry / referral service	Often you, or the aide as a contractor	Matches you with caregivers. Ask who is responsible for taxes, liability, supervision and finding a replacement.
Hiring directly	You	Most control and often the lowest rate, but you may be the employer for tax purposes, and you handle screening and backup.

Questions to ask an agency

- ☐ Are you licensed by the state (where required)? May I see your most recent inspection or survey?
- ☐ Are caregivers your employees or independent contractors?
- ☐ What background checks, references and drug screening do you do?
- ☐ What training do aides get, including dementia care? Any certifications?
- ☐ Who writes the care plan? How often is it reviewed, and does a nurse or supervisor visit?
- ☐ Can we meet the caregiver first? How do you keep the same caregiver week to week?
- ☐ What happens if the aide is sick or doesn't show up? How fast is backup?
- ☐ What is the hourly rate? Are nights, weekends, holidays or two-person transfers higher?
- ☐ Is there a minimum number of hours per visit or per week?
- ☐ Are you bonded and insured? How are complaints, injuries or theft handled?
- ☐ Can you work with long-term care insurance, VA or Medicaid programs, and handle the paperwork?
- ☐ How much notice is needed to change hours or stop service? Any contract term?

Agencies we contacted

AGENCY	PHONE	HOURLY RATE	MIN. HOURS	NOTES

During the first two weeks, watch for

- | | |
|--|---|
| ☐ The caregiver arrives on time and follows the care plan | ☐ Medications, meals and hygiene look handled |
| ☐ Your person seems comfortable, not anxious, around them | ☐ You get a call back quickly when you raise a concern |
| ☐ Visit notes or check-ins are actually happening | ☐ The home is left tidy and safe |

RED FLAGS

- × Rates quoted only by phone, with nothing in writing.
- × Vague answers about who employs the caregivers or who carries liability insurance.
- × A new caregiver nearly every visit, with no plan for consistency.
- × No supervisor visits or care plan updates, especially after a hospital stay or change in condition.
- × Pressure to sign a long contract or pay a large deposit upfront.

From the inside: ask for the agency's caregiver turnover rate and its no-show rate in the last quarter. Good agencies track both and will tell you. Also ask who your single point of contact is, and get their direct number, not just the main line.

NOTES ON AGENCIES WE SPOKE WITH

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GUIDE 2

Assisted Living

Assisted living is licensed by each state, so what's offered, who can live there and what staff can do varies widely. Pricing and move-out rules are where families get surprised most often.

Questions about care

- ☐ How do you assess care needs at move-in, and how often after that?
- ☐ How is care priced: all-inclusive, care levels, or a point system? What is each level?
- ☐ What exactly triggers a move to a higher care level and price?
- ☐ Who gives medications, and what training do they have? Is a nurse on site? Which hours?
- ☐ How many staff are on each shift, including overnight, for how many residents?
- ☐ What is your staff turnover in the last year?
- ☐ What happens in a fall or medical emergency at 2 a.m.?
- ☐ Which doctors, therapists or home health agencies come on site? Can they keep their own doctor?
- ☐ Can hospice care be provided here?

Questions about money and contracts

- ☐ What is the monthly base rate, and what does it include?
- ☐ Is there a one-time community or entrance fee? Is any of it refundable?
- ☐ How much have rates gone up each year for the past three years?
- ☐ What costs extra (laundry, transport, incontinence supplies, medication management)?
- ☐ Do you accept long-term care insurance, VA benefits or a Medicaid waiver? Now and if funds run out?
- ☐ How much notice is required to move out, and is rent prorated?

Communities we're considering

COMMUNITY	PHONE / CONTACT	BASE RATE	TOUR DATE	NOTES

Ask for these in writing

- ☐ **Move-out (discharge) criteria.** Under what conditions would they be asked to leave?
- ☐ The most recent state inspection report and any citations
- ☐ The full fee schedule, including all care levels
- ☐ A sample contract or residency agreement to read before signing
- ☐ The current month's activity calendar and a week of menus

On the tour, notice

- | | |
|---|---|
| ☐ Residents are up, dressed and engaged, not mostly in rooms or parked by a TV | ☐ The activities on the calendar are actually happening |
| ☐ Staff greet residents by name and speak to them respectfully | ☐ Hallways, bathrooms and showers are set up for walkers and wheelchairs |
| ☐ Call lights are answered quickly (ask how they track response time) | ☐ The food looks and smells good. Stay for a meal |
| ☐ Common areas and rooms are clean, without lingering odors | ☐ Outdoor space is easy and safe to get to |

RED FLAGS

- ✗ Reluctance to share the inspection report, fee schedule or move-out criteria.
- ✗ A low base rate with vague answers about how care levels are set.
- ✗ Short-staffed nights, or managers who can't say how many staff are on duty overnight.
- ✗ Pressure to sign today to 'hold the apartment' at a special price.

From the inside: the move-out criteria matter as much as the move-in tour. Ask, "If their dementia progresses or she needs a two-person transfer, can she stay?" Communities with memory care or higher-acuity licensing on the same campus can save you a second move.

GUIDE 3

Memory Care

Good memory care is less about a locked door and more about people who understand dementia. Look for consistent staff, meaningful days, and a calm approach to difficult behavior.

Questions about staff and approach

- ☐ How much dementia-specific training do staff get when hired, and every year after?
- ☐ What are staffing levels on each shift, including nights? Is staff assigned only to memory care?
- ☐ Do the same caregivers usually work with the same residents?
- ☐ How do you learn each resident's history, routines and preferences?
- ☐ How do you respond to agitation, refusing care, sundowning or exit-seeking?
- ☐ What is your approach to antipsychotic and sedating medications? Who reviews them, and how often?
- ☐ How do you handle falls, weight loss, and changes in eating or swallowing?
- ☐ How and how often will you update the family? Can we join care plan meetings?

Questions about the setting and days

- ☐ How is the unit secured, and is there safe outdoor space residents can use freely?
- ☐ What does a typical day look like? Are activities adapted for different stages?
- ☐ How are meals supported for people who need cues or help eating?
- ☐ Can residents stay as needs advance, including end of life and hospice?
- ☐ What would make them need to move out?
- ☐ How is pricing set, and what raises it as dementia progresses?

Memory care communities we're considering

COMMUNITY	PHONE / CONTACT	MONTHLY COST	TOUR DATE	NOTES

On the tour, notice

- ☐ Staff approach residents from the front, at eye level, calmly
 - ☐ Residents are engaged in something, even simple tasks, not just sitting
 - ☐ It's calm: not loud, not overstimulating, with good lighting
 - ☐ Rooms have personal items, photos or memory boxes
 - ☐ Signs, colors or cues help residents find their room and the bathroom
 - ☐ Residents look clean, groomed and appropriately dressed
 - ☐ Snacks and drinks are offered, not just at meal times
 - ☐ Staff seem patient, not rushed or frustrated

Visit more than once

Come back in the late afternoon or early evening, when many people with dementia are more restless and staffing is often thinner. Ten minutes at 5 p.m. can tell you more than an hour-long scheduled tour.

RED FLAGS

- ✗ Many residents appear sedated, or staff can't explain how medications are reviewed.
- ✗ "Activities" that are mostly television.
- ✗ No clear answer about staffing ratios, training, or turnover.
- ✗ Restraints, or residents left alone in hallways or common areas for long stretches.
- ✗ Families aren't welcome to visit at any time.

From the inside: ask to see a care plan template and the "life story" or personal history form they use at intake. Places that put real effort into knowing the person usually show it here. Ask how a new resident's first two weeks are handled. A clear settling-in plan is a strong sign.

NOTES

GUIDE 4

PACE Programs

PACE (Program of All-Inclusive Care for the Elderly) is one of the least-known options and one of the most comprehensive. It helps people who qualify for nursing-home-level care keep living at home. Some states use a different name, such as LIFE in Pennsylvania.

How it works

- One interdisciplinary team (doctor, nurses, social worker, therapists, aides, dietitian, drivers) plans and coordinates all care.
- Care centers on a PACE day center with a primary care clinic, meals, therapy and activities. The team decides how often someone attends.
- It covers everything Medicare and Medicaid cover, plus other services the team approves, including home care, prescriptions, transportation and, when needed, nursing home care.
- Care generally has to be provided or approved by the PACE team (emergencies excepted). That often means switching to the PACE doctor.

Who is eligible

- ☐ Age 55 or older
 ☐ Certified by the state as needing a nursing-home level of care
- ☐ Lives in the service area of a PACE organization
 ☐ Able to live safely in the community with PACE support at the time of enrollment

What it costs

People with Medicaid usually pay no monthly premium. People with Medicare but not Medicaid pay a monthly premium for the long-term care portion and a premium for Part D drugs. There are no deductibles or copays for approved care. Enrollment is voluntary, and participants can leave the program.

From the inside: PACE works best for people who are comfortable changing doctors in exchange for a single team that coordinates everything. Ask how many participants each primary care provider follows, how quickly the team responds to a change in condition, and how often they actually visit the home.

PACE programs near us

PROGRAM	PHONE	SERVES OUR ADDRESS?	INTAKE VISIT	NOTES

Questions to ask a PACE program

- ☐ What is your exact service area? Does it include our address?
- ☐ Who would be the primary doctor or nurse practitioner? Can we meet the team?
- ☐ How often would they attend the center, and how long are van rides each way?
- ☐ How many hours of in-home care could they receive? How is that decided?
- ☐ What happens after hours, on weekends or in an urgent situation?
- ☐ Which hospitals and specialists do you work with? How are referrals handled?
- ☐ How do you handle dementia care and family caregiver support or respite?
- ☐ If they need assisted living or a nursing home, how does PACE help and what does it cover?
- ☐ How are prescriptions filled and delivered?
- ☐ How do we appeal a decision we disagree with? How do we disenroll if it isn't working?

Good to know

- **Switching doctors is the biggest trade-off.** Talk it through with your person before enrolling.
- **Enrollment takes a few weeks.** It includes a home visit, assessments and the state's level-of-care review. Start early.
- **Not every area has a program.** Search "find a PACE plan" on Medicare.gov or contact your state Medicaid office.

RED FLAGS

- ✗ Pressure to enroll before you've met the care team or toured the center.
- ✗ Unclear answers on how in-home hours are decided or how to appeal.
- ✗ Very long transport times to the center without alternatives.

NOTES

STEP 4

Visit Scorecard

Score each option from 1 (poor) to 5 (excellent) right after your visit, while it's fresh. Weight the categories that matter most to your person.

OPTION A

OPTION B

OPTION C

CATEGORY	A	B	C	NOTES
Meets their care needs now				
Can meet needs as they change				
Staff warmth and respect				
Staffing levels and consistency				
Cleanliness and safety				
Food and dining				
Activities and social life				
Location for family visits				
Communication with family				
Transparency on fees and policies				
How our person felt there				
Our gut feeling				
TOTAL				

WHAT STOOD OUT (GOOD OR BAD) AT EACH PLACE

STEP 4

Cost Comparison Worksheet

Compare real monthly costs, not advertised base rates. Ask each provider to fill in or confirm every line.

OPTION A

OPTION B

OPTION C

MONTHLY COSTS	A	B	C
Base rate (rent, or hourly rate × hours)	\$	\$	\$
Care level / care package fee	\$	\$	\$
Medication management	\$	\$	\$
Incontinence and personal supplies	\$	\$	\$
Transportation	\$	\$	\$
Laundry, housekeeping, extra services	\$	\$	\$
Second-person or overnight fees	\$	\$	\$
Other	\$	\$	\$
Total monthly cost	\$	\$	\$

COVERAGE & INCOME	A	B	C
Insurance, VA or Medicaid paying	\$	\$	\$
Their monthly income available	\$	\$	\$
Monthly gap to cover from savings or family	\$	\$	\$

ONE-TIME & FUTURE	A	B	C
Community / entrance fee or deposit	\$	\$	\$
Typical annual increase (%)			
Months savings would last at this cost			

Tip: ask assisted living and memory care communities what the average resident pays in total, not just the starting rate, and how often residents move up a care level in their first year.

STEP 5

Family Decision Meeting

Get everyone involved on the same page, ideally with your person in the room. Agree on the decision, a backup plan, and who does what next.

DATE

WHO ATTENDED

WHAT MATTERS MOST TO OUR PERSON (IN THEIR WORDS IF POSSIBLE)

OUR NON-NEGOTIABLES (SAFETY, BUDGET, LOCATION, FAITH, PETS)

OUR FIRST CHOICE

OUR BACKUP CHOICE

TARGET START OR MOVE DATE

BUDGET WE AGREED ON (MONTHLY)

Next steps

TASK	WHO	BY WHEN	DONE

WE'LL CHECK IN ON HOW IT'S GOING ON (DATE)

CONCERNS OR DISAGREEMENTS TO REVISIT

RESOURCES

Where to Get Help

Free, official sources for finding and checking providers in your area.

RESOURCE	WHAT IT HELPS WITH	HOW TO REACH IT
Eldercare Locator	Connects you to your local Area Agency on Aging, caregiver support, meals, transportation and benefits help.	1-800-677-1116 (weekdays) eldercare.acl.gov
Area Agency on Aging	Local needs assessments, Medicaid waiver and home-care program applications, caregiver respite programs.	Through the Eldercare Locator
Medicare Care Compare	Ratings and inspection results for home health agencies, nursing homes and hospice providers.	medicare.gov/care-compare
Medicare plan finder (PACE)	Find PACE programs that serve your zip code.	medicare.gov, search "find a PACE plan"
State licensing agency	Inspection reports and complaints for assisted living, memory care and home care agencies, which Care Compare does not cover.	Search "[your state] assisted living license lookup"
Long-Term Care Ombudsman	Free advocate for residents of assisted living and nursing homes; helps resolve problems and complaints.	Through your state aging agency or the Eldercare Locator
SHIP	Free, unbiased Medicare counseling, including Advantage, supplement and drug plans.	shiphelp.org
VA caregiver support	Benefits for veterans and family caregivers, including Aid and Attendance.	caregiver.va.gov

LOCAL CONTACTS WE FOUND