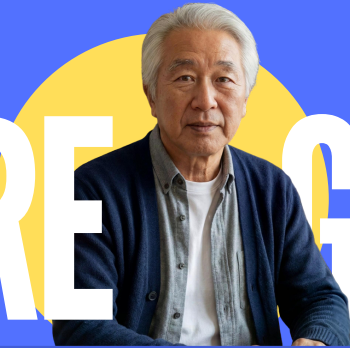


U.S. MEDICARE GUIDE



Medicaid GUIDE Respite Care: What In-Home Dementia Caregivers Need to Know



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Overview

Medicaid GUIDE Respite Care: What In-Home Dementia Caregivers Need to Know

If you're caring for someone with dementia at home, you're carrying a 24/7 responsibility. What many caregivers don't realize is that, there's a structured support system available through Medicare includes **respite care, a dedicated care navigator, and access to 24/7 help when things get overwhelming.**

Here's how it actually works—clearly and without assumptions.

First—Clear This Up

The **GUIDE Model is not Medicaid.**

It's a Medicare program created by the Centers for Medicare & Medicaid Services called:

👉 Guiding an Improved Dementia Experience (GUIDE) Model

What the GUIDE Model Provides

Once enrolled, you receive:

- A **care navigator (care coordinator)**
- A personalized dementia care plan
- **Respite care services**
- Caregiver education and training
- **24/7 support access for urgent situations**

The Care Navigator (Your Direct Line of Support)

You are assigned a **care navigator**, and this is where many people expect a simple public phone number.

Here's the reality:

👉 There is **no universal phone number for GUIDE care navigators**

Instead:

- Your **specific GUIDE provider assigns a navigator**
- You are given a **direct phone number** to that individual or care team
- This number is **only available after enrollment**

What your navigator helps with:

- Scheduling respite care
- Managing behaviors and care plans
- Coordinating appointments and services
- Acting as your **first call for non-emergency issues**

The 24/7 Support Hotline (Exact Numbers You Can Use)

1. If You Are Enrolled in GUIDE

- You will receive a **dedicated 24/7 hotline number from your provider**
- This is **not public or national**
- It connects you directly to your care team or on-call clinicians

👉 This is intentional—so you're speaking with people who know your case, not a generic call center.

2. If You Are NOT Enrolled Yet (Use This Now)

You still have access to immediate dementia support:

📞 Alzheimer's Association 24/7 Helpline
1-800-272-3900

This line provides:

- Crisis support
- Caregiving guidance
- Help with behavior changes
- Direction to local resources

It's often the **fastest way to get real-time help** while you're working on enrolling in GUIDE.

3. Medicare General Support Line

For help finding GUIDE providers:

 Medicare

1-800-MEDICARE (1-800-633-4227)

They can:

- Help locate participating providers
- Confirm eligibility basics
- Direct you to enrollment pathways

What Respite Care Looks Like

Respite care gives you **temporary, planned relief** from caregiving.

This may include:

- In-home caregiver coverage
- Adult day care services
- Short-term facility stays (varies by provider)

Important:

This is **scheduled and approved through your care navigator**, not something you arrange independently.

Who Qualifies

The person you're caring for must:

- Have Medicare (Part A and B)
- Have a diagnosis such as Alzheimer's disease or another dementia
- Live at home or in the community
- Not be enrolled in hospice at the time of joining

AMERICAN COUNCIL ON AGING can help determine your eligibility [Medicaid Long-Term Care Eligibility Test](#)

How to Apply

There is no direct sign-up form.

You must enroll through a provider:

1. Ask your doctor:
"Do you participate in the GUIDE dementia model?"
2. Contact local memory clinics or health systems
3. Call Medicare (number above) for participating providers
4. Complete enrollment through that provider

Cost

- Covered under Medicare
- Some copays may apply
- Respite care is **partially covered**, depending on your plan

Why the Phone Numbers Work This Way

It may feel frustrating that there isn't one simple "GUIDE hotline."

But there's a reason:

- Dementia care is **case-specific**
- Providers need **context about the patient**
- A centralized hotline wouldn't be able to give safe, personalized guidance

So instead, GUIDE is designed to give you:

- A **dedicated navigator number**
- A **provider-specific 24/7 line**
- Backup national support (Alzheimer's Association)

Numbers

Here are the exact numbers you can use today:

- **Immediate dementia support (anytime):**
☎ 1-800-272-3900 (Alzheimer's Association)
- **Find GUIDE providers / Medicare help:**
☎ 1-800-633-4227 (Medicare)
- **Your personal care navigator + 24/7 GUIDE line:**
👉 Provided **after enrollment**

You don't need to wait for a breaking point to get help.
The structure is there—you just need to connect into it.

How to Combine GUIDE + Medicaid (Your state) Caregiver Strategy

You're not choosing one or the other.
The strongest setup is **layering both programs together**.

Think of it like this:

- **GUIDE (Medicare)** = coordination, navigator, structured respite funding

- **Medicaid (Your state's waivers)** = long-term daily care support + additional hours

Step 1: Lock in GUIDE First (Your Foundation)

Through the Centers for Medicare & Medicaid Services

👉 Guiding an Improved Dementia Experience (GUIDE) Model

What you get immediately:

- Care navigator (your point person)
- 24/7 support line (provider-specific)
- Up to **\$2,500/year in respite care**
- Care plan + coordination

Local State's Providers You Can Contact Right Now

Look for providers:

- Participate in GUIDE
- Help with enrollment
- Provide dementia-trained caregivers

Step 2: Layer Your State's Medicaid Waiver (This Is Where Most Miss Out)

HCBS (Home and Community-Based Services) Waivers. You can use this one if it applies to your state

[I've included an additional page with phone numbers to contact in the hopes of making this process easier for you.](#)

The key one for dementia:

👉 **Aged & Disabled (A&D) Waiver**

What Medicaid Adds (That GUIDE Does NOT Cover)

Service	GUIDE	Medicaid Waiver
Care navigator	✓	✗
24/7 support line	✓	✗
Respite care	✓ (limited ~\$2,500/year)	✓ (more hours possible)
Daily caregiving help	✗	✓
Long-term coverage	✗	✓

👉 Translation:

GUIDE gives **structure + support**

Medicaid gives **hours + manpower**

Step 3: Apply for Your State's Medicaid Waiver

You apply through your state's **Aging & Disability Resource Center (ADRC)**

What they evaluate:

- Income (strict limits)
- Medical need (help with daily activities)
- Level of care required

What You Can Get (Realistically)

If approved for Medicaid waiver:

- In-home caregiver hours (multiple days/week)
- Additional respite beyond GUIDE limits
- Home modifications (in some cases)
- Adult day services

Step 4: How They Work Together (This Is the Strategy)

Your GUIDE Care Navigator:

- Builds your dementia care plan
- Helps identify caregiver burnout
- Coordinates services

Your Medicaid Case Manager:

- Approves **hours + services**
- Handles long-term care logistics

👉 These two roles **should work together**

Real Example (What This Looks Like in Practice)

Let's say:

- GUIDE gives you:
 - Care navigator
 - \$2,500/year respite
 - 24/7 hotline
- Medicaid waiver adds:
 - 20–40 hours/week caregiver help
 - Extra respite hours

👉 Result:

You go from **doing everything alone** → to having **scheduled, ongoing help + backup**

Step 5: Use Backup Support While You Wait

Enrollment can take time.

Use this immediately:

📞 Alzheimer's Association
24/7 Helpline: 1-800-272-3900

They can:

- Help you find local Indiana resources
- Guide you through applications
- Support you in crisis moments

Important Reality (You Should Know This Going In)

From both official rollout data and caregiver feedback:

- GUIDE is still expanding (not all areas fully staffed)
- Some providers rely on **virtual support first**
- Enrollment can take persistence

👉 But once you're in, the structure is significantly better than going solo.

Your Exact Action Plan (No Guessing)

1. Call one of the local providers above
2. Ask: "Do you enroll patients into the GUIDE program?"

3. Start enrollment
4. Call Your State's ADRC → apply for A&D waiver
5. Use Alzheimer's Association line while waiting

Bottom Line

If you only use one program, you'll still feel overwhelmed.

If you **stack them correctly**, you get:

- A **navigator guiding decisions**
- A **24/7 number when things escalate**
- **Respite built into your schedule**
- **Actual hands-on help in your home**

That combination is what prevents burnout—not just information.

Step 1: Call the Right Entry Point (Your State's ADRC)

Your first official gateway for Medicaid waiver support is:

👉 Your State's **Family and Social Services Administration (FSSA)**
☎️ **1-800-457-8283**

This connects you to Indiana's **Aging & Disability Resource Center (ADRC)**.

What to say (keep it simple and direct):

"I'm an in-home caregiver for someone with dementia. I need to apply for the Aged & Disabled Waiver and get a functional assessment scheduled."

That wording triggers the correct pathway faster.

Step 2: Apply for Your State's Medicaid (If Not Already Approved)

👉 Your State's Medicaid Office
☎️ **1-800-403-0864 Indiana Medicaid Office (example)**

You can also apply online through FSSA, but calling helps avoid delays if your case is complex.

Financial Qualification (Your State's Reality Check)

Medicaid eligibility is strict. For 2026 (approximate ranges):

For the person receiving care (could be different in each state) Must contact them to get the exact amount:

- Income limit: ~**\$2,800/month**
- Assets: typically **under \$2,000**

If they’re over income:

- Certain states allows a **Miller Trust (Qualified Income Trust)** to still qualify

👉 This is where many people get incorrectly denied—don’t stop here if over income.

Step 3: Functional Assessment (This Is What Actually Qualifies You)

Even if finances pass, approval depends on **care needs**.

They will evaluate ability to perform:

- Bathing
- Dressing
- Toileting
- Mobility
- Eating
- Cognitive impairment (critical for dementia cases like Alzheimer’s disease)

👉 Dementia patients often qualify **based on supervision needs alone**, not just physical limitations.

Step 4: What Hours You Can Realistically Expect

Let’s be direct—this is what most caregivers want to know.

Typical State’s Waiver Outcomes:

Level of Need	Weekly Care Hours
Mild support	10–15 hours
Moderate dementia	20–30 hours
Advanced dementia	30–40+ hours

These hours can include:

- Personal care aides
- Homemaker services
- Respite care

Step 5: Stack This With GUIDE (Where It Gets Powerful)

👉 Guiding an Improved Dementia Experience (GUIDE) Model

GUIDE gives you:

- Care navigator
- Structured care plan
- ~\$2,500/year in respite (depending on each state)
- 24/7 support line (provider-specific)

Medicaid Waiver adds:

- Weekly caregiver hours
- Long-term in-home support
- Additional respite beyond GUIDE limits

How They Work Together (Operationally)

- Your **GUIDE care navigator**:
 - Identifies burnout risk
 - Helps schedule respite
 - Coordinates medical care
- Your **Medicaid case manager**:
 - Approves and adjusts caregiver hours
 - Handles long-term service authorizations

👉 If these two aren't aligned, you lose efficiency—so always inform each side about the other.

Step 6: GUIDE Enrollment (Local State's Options)

You'll need a participating provider.

Ask directly:

"Are you a GUIDE Model participant through Medicare?"

If they say yes, they will:

- Assign your **care navigator**

- Give you your **direct number + 24/7 support line**

Step 7: Immediate Help While You Wait

Do not wait weeks without support.

 Alzheimer's Association
24/7 Helpline: 1-800-272-3900

They can:

- Walk you through behavior issues in real time
- Help locate Indiana resources
- Guide you through applications

What Most Caregivers Miss (Critical Insight)

1. **You can have BOTH programs at the same time**
2. GUIDE alone is not enough for daily help
3. Medicaid alone lacks coordination and crisis support
4. Together, they create a **complete system**

Your Exact Action Plan (Do This in Order)

1. Call **FSSA (ADRC)** → 1-800-457-8283
2. Start Medicaid application (if needed)
3. Request **functional assessment**
4. Contact a GUIDE provider → start enrollment
5. Use Alzheimer's helpline for immediate support

Bottom Line

If you execute this correctly, you move from:

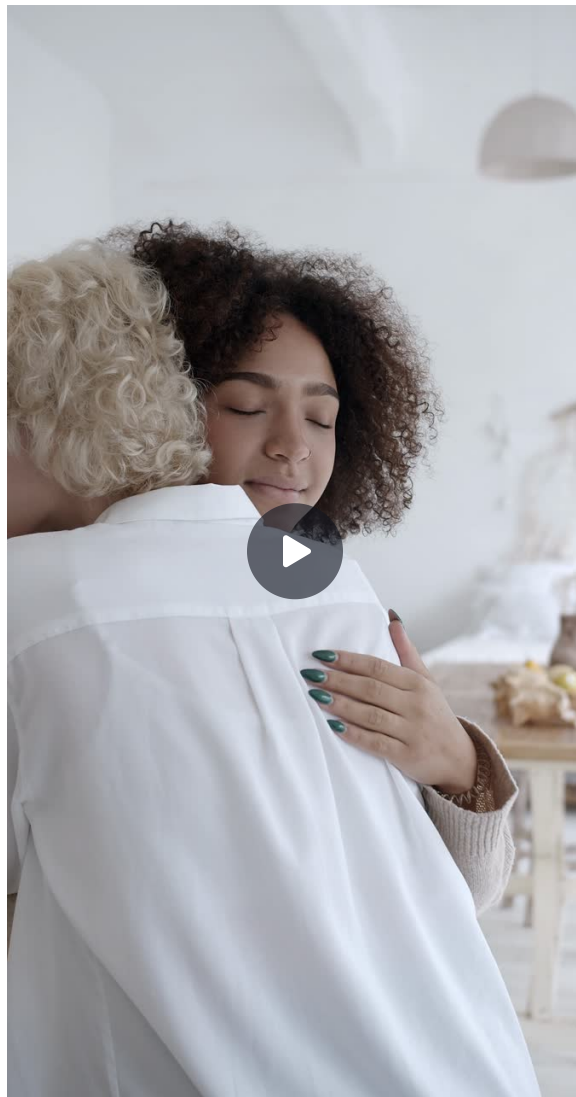
 Doing everything alone

 To

 Having:

- Weekly in-home help
- A care navigator guiding decisions
- A number to call at 2 a.m. (24hr hotline)
- Built-in respite so you can step away

That's the difference between surviving caregiving and sustaining it.



Contacts

Here are the main national Medicare, Medicaid, HCBS Waiver, caregiver support, dementia support, and financial assistance contacts that can help caregivers and loved ones in every U.S. state.

Main Medicare Contacts

Official Medicare Website

[Medicare.gov Official Website](https://www.medicare.gov)

Medicare Main Phone Number

1-800-MEDICARE (1-800-633-4227)

TTY: 1-877-486-2048

Available 24/7.

Medicare Caregiver Resources

[Medicare Caregiver Resources](#)

Medicare GUIDE Program (Dementia Caregiver Support)

[CMS GUIDE Program Official Page](#)

The Medicare GUIDE program offers:

- Dementia care coordination
- Caregiver education
- 24/7 support line
- Respite care funding
- Community resource navigation
- Behavioral health support

The GUIDE model officially began nationwide in 2024.

State-by-State Medicaid & HCBS Waiver Directory

This official CMS page includes:

- Every state Medicaid office
- State waiver programs
- Enrollment contacts
- HCBS program links
- Eligibility contacts
- Renewal help

[State Medicaid Office Directory \(All 50 States\)](#)

This is the most important state-by-state directory for:

- HCBS waivers
- Long-term care
- Medicaid caregiver support
- Home care programs
- Respite care
- Adult day services
- Financial assistance

HCBS Waiver Information

Official HCBS Waiver Information

[HCBS Waiver Programs Official CMS Page](#)

HCBS Waivers may provide:

- In-home caregivers
- Adult day care
- Transportation
- Home modifications
- Meal assistance
- Respite care
- Skilled nursing
- Memory care support
- Behavioral health services

Nearly every state operates HCBS waiver programs.

National Caregiver & Dementia Help Lines

Alzheimer's Association

24/7 Dementia Help Line:

1-800-272-3900

Website:

[Alzheimer's Association](#)

Offers:

- Crisis support
- Dementia education
- Caregiver support groups
- Local services
- Safety planning
- Financial resource guidance

Family Caregiver Alliance

Website:

[Family Caregiver Alliance](#)

Offers:

- Caregiver education
- Burnout support
- Legal guidance
- State resource locator
- Self-care resources

Eldercare Locator

Phone:

1-800-677-1116

Website:

[Eldercare Locator](#)

Connects caregivers with:

- Meals
- Transportation
- Respite care
- Legal aid
- Financial aid
- Home services
- Senior programs

National Alliance for Caregiving

Website:

[National Alliance for Caregiving](#)

Mental Health & Crisis Support for Caregivers

988 Suicide & Crisis Lifeline

Call or text: 988

Website:

[988 Lifeline](#)

Provides:

- Emotional crisis support
- Suicide prevention
- Caregiver overwhelm support
- Mental health crisis counseling

Financial Assistance Resources

BenefitsCheckUp

Website:

[BenefitsCheckUp](#)

Helps find:

- Medication assistance
- Food programs
- Utility help
- Housing assistance
- Senior benefits
- Caregiver support programs

Social Security Administration

Phone:

1-800-772-1213

Website:

[Social Security Administration](#)

Veterans Caregiver Assistance

U.S. Department of Veterans Affairs

Caregiver Support Line:

1-855-260-3274

Website:

[VA Caregiver Support Program](#)

Offers:

- Respite care
- Training
- Financial stipends
- Mental health services
- Home support

Important Medicare GUIDE Notes

Many caregivers are still unaware the GUIDE program exists. Community reports show families are receiving:

- Monthly caregiver check-ins

- In-home support coordination
- Limited respite hours
- Dementia-trained care teams
- Care navigation assistance

Some users report availability varies by region because the program is still expanding nationally.

Conclusion



We sincerely hope this information about our United States Medicare Guide helps you while you are helping someone else. We understand that what you are going through is very difficult, and we hope to offer you support with this quick reference.