Caregiving Years
Training Academy

Making the Case for Reimbursement

590 Family Caregivers on the Scope and Value of Their Work

Family caregivers are not unpaid.
They are non-reimbursed.

Denise M. Brown

The Caregiving Years Training Academy · October 2026

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Updated October 10, 2026: revised the description of the kidney failure review in Section VI.

Executive Summary

The Caregiving Years Training Academy · Denise M. Brown · October 2026

The wrong question

For nearly a century, caregiving research focused on burden. The family caregiver is burdened, a victim. With the spotlight on burden, the scope of a family caregiver's work and the value that work brings to our communities and health care systems remains overlooked. We also miss the opportunity to showcase family caregivers as the leaders they are. Each is the CEO of a caregiving enterprise.

The research also relies on a screening question for family caregivers, largely unchanged since 1997, that starts from a caree's condition rather than the family caregiver's work. As early as 2001, AARP found that nearly half of the people doing this work didn't call themselves caregivers. Because that question overlooks the family caregiver's scope of work, we have not correctly counted the number of family caregivers and the value they deliver.

When we ask the wrong question and keep the family caregiver's value hidden, we leave that family caregiver vulnerable in our current political climate. Rather than looking to increase support for family caregivers, some states now look to pull back on that support.

Meanwhile, family caregivers have asked me one question more than any other for 30 years: How do I get paid for doing this?

To answer it, this paper asks a different question than research has asked: what is the family caregiver's scope of work and the value of that work?

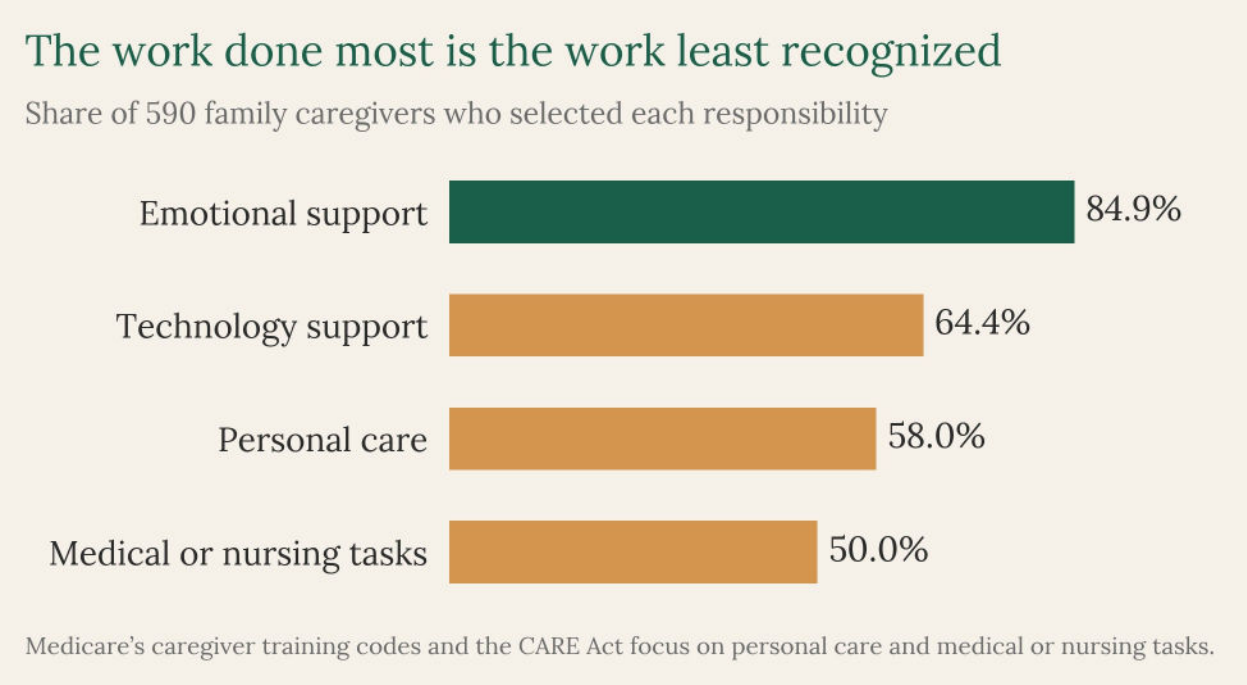
What we did

In May 2026, we launched the Non-Reimbursed Family Caregiver Savings Calculator. The tool asks family caregivers to name their own work across 53 care responsibilities within the Nine Caregiving Domains™ (Advocating, Assessing, Being, Communicating, Deciding, Managing, Planning, Providing, and Sustaining). Based on the family caregiver's selections, the tool then values that work at a professional market rate. The tool does not ask any questions about the caree. Between May 10 and October 3, 2026, 590 family caregivers completed it.

590	8.3 of 9	84.9%	$114,400	$1.19 billion
family caregivers	caregiving domains, on average	provide emotional support	median annual value (average $172,718)	estimated value across their experiences

What family caregivers told us

- **The role is broad from the start.** Family caregivers selected an average of **34.7 of 53** care responsibilities and **8.3 of 9** domains. In their first year, they already work across 8.1 domains.
- **The work the system doesn't recognize is the work done most. 84.9%** provide emotional support. 58.0% provide personal care and 50.0% provide medical or nursing tasks. Medicare now pays for training for family caregivers but does not offer any effective intervention to support the family caregiver's emotional wellbeing.
- **Technology support outranks personal care**, 64.4% to 58.0%, yet we provide no relief for these family caregivers doing the work to keep their carees connected to their world through their computers and devices.
- **Worry is part of the work. 81.4%** selected Worries & Uncertainty. Those who did report an average of 67.3 total hours a week, compared with 35.5 for those who didn't.
- **The hours are long.** Family caregivers report an average of 61.4 total hours a week (median 40) and 9.4 total years (median 6), combined across their caregiving experiences. Those experiences may not have happened at the same time. 11.4% report 168 hours a week, the equivalent of every hour of every day.
- **The work is worth far more than it is paid.** The average family caregiver's work is worth **$172,718 a year** (median $114,400), valued at a skill-based rate of $55 an hour, wages only. Together, these family caregivers reported an estimated $1.19 billion in non-reimbursed work across all their caregiving experiences, crossing $1 billion with the 502nd response.

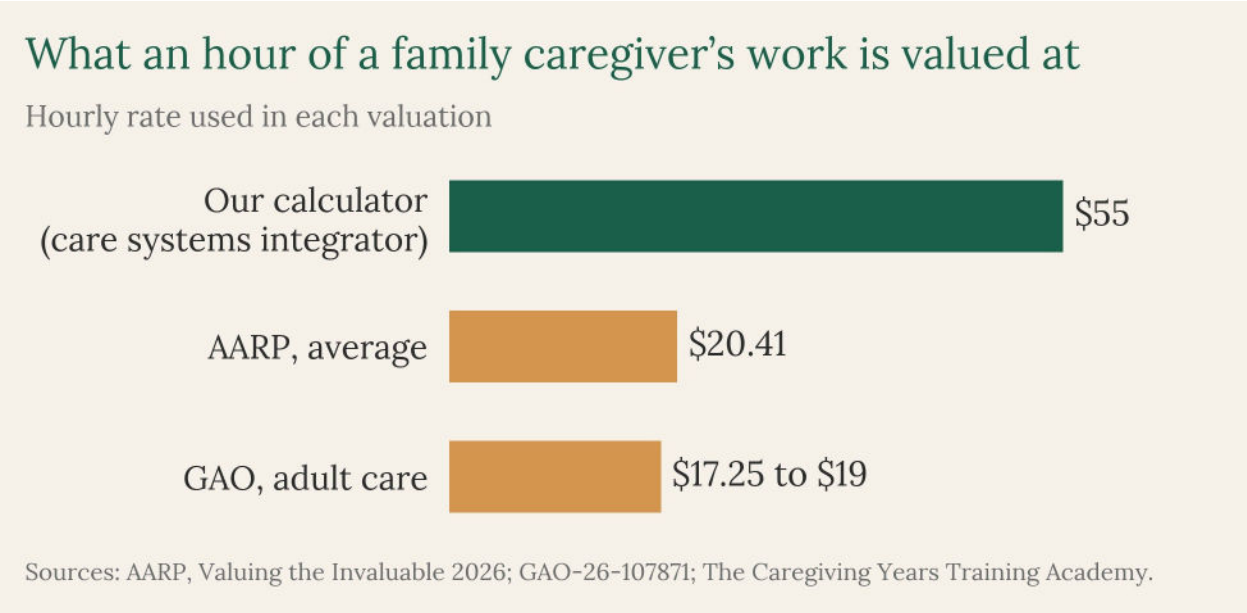


Non-reimbursed, not unpaid

Family caregivers are not informal or unpaid. They are **non-reimbursed**. Every other system that touches the caree has a billing code, and family caregivers doing the work do not, even as they do the work the systems cannot.

The rates in use confirm the gap. AARP values a family caregiver's hour at $20.41 on average, with rates that vary by task. In September 2026, the U.S. Government Accountability Office valued caring for adults at personal care aide and nursing assistant wages, $17.25 to $19 an hour, under the heading of unpaid household work. GAO values that care at $51 to $64 for a typical 3.15-hour day.

But family caregivers are not direct care workers. Family caregivers don't work a shift, don't take off for holidays and weekends, and often don't have back-up to call in sick. The results generated by our Non-Reimbursed Family Caregiver Savings Calculator reflect that. The family caregiver's highest level of work more closely resembles that of a care systems integrator, valued at $55 per hour. The caregiving space undervalues the family caregiver's hour by more than $30 per hour or, by GAO's own calculation, by more than $100 per day.



A family caregiver's hour should be valued by their skill, not by the task in front of them.

What the field missed

The instruments used to measure family caregivers, led by the 46-year-old Zarit Burden Interview, assume the caree is the source of burden. The results of that Interview often serve as the price of entry for help for the family caregiver. If the caree is their burden, then family caregivers may qualify for programs and services. If the family system is their burden, the Interview doesn't see their burden so may determine that those family caregivers don't need support.

In our stress survey of 1,365 family caregivers, the top source of stress was not the caree. It was **"I miss my life" (69.3%)**. If our assessment tools integrate questions about a family caregiver's scope of work and source of stress, then we create a complete picture of a family caregiver's experience. With that global view, we can be specific in how to support that family caregiver.

The definitions also miss a significant amount of the work family caregivers do. Tim Otis spends about five hours a week serving as the messenger between his father and his sisters. "I never thought that was part of caregiving," he told us. When definitions miss his work, we miss the opportunity to intervene with effective, timely support.

Three achievable changes

We believe we can reduce stress and increase quality of life for family caregivers when we expand current legislation and billing codes:

1. **Expand Community Health Integration and Principal Illness Navigation billing codes to formally include family caregivers.** We want Centers for Medicare & Medicaid Services to state that the family caregiver, as well as the patient, can receive the social and emotional support these Medicare codes already authorize, delivered by a professional trained to coach family caregivers.
2. **Open home health to coaching.** A trained auxiliary professional can coach the family caregiver under Part B alongside the home health team, as new revenue rather than a duplicate service. Coaching involves emotional support rather than teaching hands-on care. Family caregivers want to connect with a professional who can listen to them and work to create strategies for coping and managing.
3. **Add an aftercare plan to CARE Act discharge.** State CARE Act discharge notifications should include an aftercare plan for the family caregiver with referrals to support and help for them, including to a caregiving coach, just as these plans already include referrals to home health and equipment suppliers for the caree.

How we pay for it

Funding reimbursement is the challenge we are working to resolve now. Models already exist: dedicated revenue (New Jersey's casino-funded respite program), social insurance (Washington's WA Cares Fund, which can pay family caregivers), direct payment (the VA, Medicaid self-direction, and now private long-term care insurance), and a research set-aside: 10% of each award that funds research on family caregivers, directed to reimbursing them. Any mechanism should pay for skill rather than task, follow the family caregiver rather than the diagnosis, draw on a dedicated source, and **build in an escalator from day one**. New Jersey's respite funding sat at $5.3 million a year from 2002 to at least 2014 because nothing required it to grow.

What you can do

- **Family caregivers:** Calculate your own value at caringourway.com/value. Every response makes the next number harder to ignore.

- **Policymakers:** Act on the three changes above, and build any reimbursement program with a dedicated source and an escalator. In addition, build a reimbursement budget into any funding meant to serve family caregivers.
- **Researchers and funders:** Start from the family caregiver's scope of work, and work on the funding question with family caregivers, not about them.

This is a self-selected sample of family caregivers who chose to use the calculator. It describes the composition and value of their work, not national prevalence. Hours, years and values are family caregivers' own estimates across their caregiving experiences. Full methodology, including how duplicate submissions were handled and how AI was used, is in Section II of the full report.

I. Introduction — The Wrong Question

When I launched a business to support family caregivers in 1995, I focused on emotional support, launching a print publication that felt like a support group meeting mailed monthly to family caregivers. I named it "Caregiving!" rather than "Caregiver!" because I didn't want to put the family caregiver in a box. I wanted them to use the language for this role that works for them.

When I shared about my work during the early years of my business, I regularly got this question: So you train family caregivers? Nope, I would answer, I provide emotional support to help them cope.

In 1995, I understood that the caregiving experience was an emotional one.

But research makes a different assumption.

One Role, Several Definitions

AARP and the National Alliance for Caregiving define family caregivers as "adults providing ongoing care over the past year to adults or children with complex medical conditions or disabilities." The screening question behind that definition has changed little since the first national caregiving study in 1997.

This definition, though, starts from the caree's condition and the word "care." It leads to the assumption that the caregiving experience consists of completing tasks for someone who is ill or disabled.

A caregiving experience is much more than this. The AARP/NAC definition also misses too many family caregivers, especially early in their experience, before they would call what they do "care." For some family caregivers, hands-on care may only begin toward the end of the caregiving experience. I coach a client caring for her husband for 11 years. He recently started receiving hospice services and she only recently began helping him with dressing. She provides 24/7 care for him (he can't live without her) but I wonder if the AARP/NAC definition speaks to her. She may not see herself as providing care to a husband who has complex medical conditions.

Because this definition is too narrow, I regularly encounter family caregivers who ask me if they "qualify" for help and support. They'll say: "I don't do hands-on care. Can I join your community?"

I always answer: "Yes! Join us. You deserve support. The best day to build your support is on your best day so you have it on your worst."

With such a restrictive definition, an individual who provides emotional support after a family member receives a diagnosis may not think of themselves as a family caregiver. But providing emotional support is a huge part of a caregiving experience. When we have a broader definition, we reach family caregivers early in their experience which means we can intervene with help and support right away so it builds as their stress and responsibilities increase.

The field has known this for 25 years. In a study published in 2001, AARP surveyed 4,037 adults. It found that 34% were caregivers, based on a description of the help they provide, including arranging services and checking in regularly. Only 19% both fit that description and called themselves a caregiver. Nearly half of the family caregivers AARP found didn't recognize themselves in the word. AARP's own researchers concluded that reaching family caregivers requires "both the term caregiver and a definition of what caregivers are."

Today's national screener, used by AARP and the National Alliance for Caregiving, does not use the word caregiver. It asks whether anyone in the household "provided unpaid care to a relative or friend 18 years or older to help them take care of themselves." Its examples include personal needs, household chores, managing finances, arranging outside services and visiting regularly. That is broader than hands-on care. But a person still has to see what they do as "care" to answer yes, and the examples do not mention providing emotional support, managing worries, assessing situations for safety, communicating with family members and providers, advocating for the best care or making decisions about providers, treatments and next steps.

We don't have one definition of a family caregiver. We have several. In 2026, Pew Research Center asked adults with a parent age 65 or older, "Do you consider yourself to be a caregiver for a parent age 65 or older?" Of those asked, 24% said yes (Pew Research Center, 2026). That question depends on a person using the word caregiver for themselves, the same word nearly half of the people doing this work didn't use in AARP's 2001 study. The Centers for Disease Control and Prevention asks whether, in the past 30 days, a person provided "regular care or assistance to a friend or family member who has a health problem or disability." Each question finds a different group of family caregivers. None starts from the full scope of the work.

Researchers have named this problem for years. A 2010 comparison of eight national surveys found estimates of the number of caregivers of older adults with disabilities ranging from 2.7 million to 36.1 million, depending on how each survey decided who counts (Giovannetti & Wolff, 2010). In 2024, the National Academies again cited "a lack of consistent definitions of caregiving" as a reason the estimates vary.

How do I define caregiving? I ask a simple question: Who do you worry about? The worry defines us in a caregiving role because nearly all of us carry it. 81.4% of family caregivers who used our calculator selected Managing Worries & Uncertainty.

In addition to a definition that's too restrictive, research assumes it understands the family caregiver's burden: the relationship with a caree. That may be part of the family caregiver's burden. In my experience, the larger burden on the family caregiver comes from the disorganized, short-staffed systems. The payer determines the length of stay for a caree's hospitalization and what help will be available post-discharge. Family caregivers then have to make it happen: be available on discharge day, get approval to take time off from work, find someone to pick up the kids after school, figure out new treatments and care plans, keep a caree calm, confirm the doctor wrote orders for services like home health, and update family members and other providers. The system delegates the work to the family caregiver but doesn't reimburse the family caregiver or provide support.

I knew the definition of a family caregiver missed the mark. I knew the burden came from the systems. I just didn't have the data to show the full scope of the work until I launched the Non-Reimbursed Family Caregiver Savings Calculator in May 2026.

The calculator asks family caregivers about their own experience across the Nine Caregiving Domains™ and 53 types of caregiving within those domains.

Our calculator helps a family caregiver describe their scope of work without us needing to know a caree's diagnosis.

When we define the complexity of a family caregiver's reality — their worries, their decisions, their stress, their definition of peace of mind — we finally collect data about a caregiving experience.

That's caregiving research.

That's not the research that's been happening.

This paper takes an honest look at our field's misfires, and the cost of those misfires for family caregivers. In this paper, we look at ways to correct those misfires.

Nearly 100 Years of the Same Finding

In May 2026, a researcher at the University of Lucerne published a peer-reviewed paper in the Journal of Multidisciplinary Healthcare with a quiet but devastating conclusion. After reviewing decades of family caregiver burden research, Armin Gemperli wrote:

"At this point of diminishing returns, additional studies yield more repetition than revelation." — Gemperli, 2026

He called it research waste, a great term I wish I had used when I first began writing about how much we over-research the caregiving experience. In August 2010, I published a blog post asking whether the caregiving field needed more research. I argued that we were

over-researching the experience and underspending on the services that would actually help family caregivers. I wrote:

"Researching a disease is about finding a solution. Researching an experience is about making it better."

Family caregiver burden, Gemperli noted in his abstract, has been documented for "nearly a century." Since then, an ever-expanding body of research repeatedly confirms that family caregivers across diverse conditions and cultures commonly experience high levels of burden.

Nearly 100 years. The same finding. Over and over.

Rather than advancing and making positive impacts, science simply stalls as it runs in place.

The Caregiving Research Didn't Change the Experience

The research field has never had to answer an important question. If the research made a difference, why aren't family caregivers less stressed today than they were 30 years ago?

As a professional working with family caregivers since 1990, I witness the caregiving experience first-hand. I can tell you: Family caregivers are not less stressed.

I decided I needed data to reflect this. In December 2015, I began an ongoing stress survey. 1,365 family caregivers have completed it. They rate their stress on a scale from 1 to 5. The average is 4.08. 77.4% of family caregivers rate their stress a 4 or a 5.

The stress remains.

The Premise That Was Never Questioned

The burden research repeatedly focuses on asking family caregivers about their burden as it relates to the relationship they have with their caree. Researchers ask that question using the same instruments, built on the same assumptions, validated against each other, and published in the same journals.

Every major research instrument in the family caregiving field accepted, without challenge, the same assumption: that caregiving is something that happens to the family caregiver, that the family caregiver is a victim to the experience.

Burdened.

That assumption means that researchers never considered a family caregiver as leading a caregiving experience. They never saw family caregivers as the CEOs they are as they oversee a complex, complicated, multi-year project: keeping their carees alive. Research never considered family caregivers as individuals contributing value to the 19 Caregiving Systems™. They never thought that the systems rely on the family caregiver to do the work that the systems simply cannot.

The burden research did not fail because researchers were careless or dishonest. It failed because of instruments consistently developed from the wrong premise.

Thirty years of consistent data built on the wrong premise is thirty years of consistently missing the family caregiver. Because of that incorrect premise, the space is cluttered with "solutions" that don't resolve the problems family caregivers face. Over the past 14 years, care coordination app after app launched with fanfare and then quietly closed. Developers built these apps believing the family caregiver would take the time needed to upload data to the app, organize information within the app and then coordinate care using the app. Care coordination is system coordination; family caregivers manage the 19 Caregiving Systems™. How many of those systems, like the physician's office, the home care agency, the adult day program, the insurance care manager, will join the family caregiver in using that app? In addition, an app is not going to change the behavior of a sibling who won't help. The sibling who won't help won't help. An app meant to coordinate care by bringing everyone together ultimately leaves the family caregiver alone with yet one more tool.

A family caregiver once shared her experience with an app she excitedly discovered that she thought would solve the problem of her uninvolved siblings. She downloaded the app, uploaded all the information about her caree and sent a lovely email inviting her siblings to join her. Not one joined. That's a soul-crushing experience. That family caregiver will think twice about how she asks for help because, going forward, she'll want to protect herself from another painful experience.

Developing and releasing an app takes an investment. Consider Carely, which raised $2.5 million for its care coordination app. (Carely acquired my former website, CareGiving.com, in 2020.) Carely discontinued the app on July 1, 2024.

Research supports what family caregivers tell me. In 2025, researchers at Northwestern Medicine reviewed 21 apps built to support family caregivers. The apps earned an average rating of 2.7 out of 5. Only 57% included helpful features such as medication reminders or shared calendars. Many were built without input from family caregivers (Petrakos et al., 2025).

The burden premise drives what gets developed. What family caregivers need (relief from the work) is still often overlooked. We waste time, money and resources while leaving family caregivers struggling to get the help and support they want and need. We add to their work instead of relieving them of it.

What We Should Have Done Instead

We should have asked different questions earlier.

Not what tasks does the family caregiver complete for the caree. Instead: how does the family caregiver manage an experience across the 19 Caregiving Systems™?

Not how hard is caregiving. Instead: what takes up too much time during a caregiving day?

Not how does caregiving diminish a family caregiver. Instead: what is the family caregiver's work worth?

Not how one-dimensional a family caregiver is. Instead: what sophisticated skills does a family caregiver use to sustain their own quality of life?

Not how do we measure burden. Instead: how do we reflect value?

Family caregivers have been asking about value all along. For 30 years, they have asked me one question more than any other: How do I get paid for doing this? In a 2025 national survey, 68% of family caregivers said a program that pays them would help (AARP and National Alliance for Caregiving, 2025). We need to answer family caregivers with a program that reimburses them for their value.

If we measure the value, then we can argue that family caregivers can no longer do the work of the system for free. But over-researching the wrong thing is only half the problem. The other half is what the field chose not to research at all.

A Body of Knowledge About the Role, Not the Person

My parents loved me. They really didn't get me.

My mom wanted me to be married and raise a family. My dad wanted me to have a successful business. My struggling solo entrepreneur life as a single woman just confounded them.

My parents didn't see me as I was. They saw me as I failed to be. Every observation they made, every solution they offered, started from a picture of me that wasn't mine.

The research field did the same thing. **It decided who family caregivers are — burdened, diminished, defined entirely by the caregiving role — and then spent decades confirming it.** Every study started from the same picture. Every finding confirmed the same image.

Nobody stopped to ask whether the picture was right.

The systems around family caregivers — medical, legal, financial, the organizations that claim to serve them — function more smoothly when the family caregiver has no competing demands. No job to protect. No relationships to tend. No self to sustain.

Everyone else in the system benefits when the family caregiver disappears entirely into the role.

Researchers never asked how family caregivers keep a life during caregiving. They didn't ask because they never saw the life.

It was a body of knowledge about the role. Not the person.

Here's what that costs.

In that stress survey, the number one reported cause of stress wasn't the medical tasks. It wasn't the financial strain. It wasn't the physical exhaustion.

It was this: *I miss my life.* 69.3% of respondents selected that choice.

I coach a family caregiver through weekly one-hour sessions. During each session, she expresses her sadness over the days spent solving problem after problem, over the responsibilities she carries alone, and over the change in her husband into someone she no longer recognizes. She tells me every week she misses her life. I always listen. Sometimes we strategize. Often we talk about the relentless pressure she carries. At the end of every call, she thanks me profusely. It's how she tells me the hour helps.

When we built the Non-Reimbursed Family Caregiver Savings Calculator and asked 590 family caregivers what they actually do, 90.7% selected Sustaining — maintaining their own health, their home, their nervous system, their routines, their life.

They actively work to hold onto themselves without any research instrument ever valuing it.

A definition that reduces a family caregiver with multiple roles to a single one will only ever find that one role. It will confirm the same findings, fund the same studies, and miss the same person, decade after decade.

The System Collects What It Needs

"*Is this for all ages and disabilities?*"

Someone asked me this question about our calculator on LinkedIn. It's a fair question. It's also a window into exactly how the system works.

She didn't ask: Is this for me? She asked: Which category does this fit?

That is the cost of thirty years of walls. The walls weren't built by family caregivers. They were built by the systems that fund and study them.

Every system builds the tool it needs. A health plan needs to manage risk, so it screens family caregivers for burnout and gets a risk score. A hospital needs to document discharge, so it records the family caregiver's name. A disease organization needs a fundable population, so it organizes support by diagnosis.

Each system's needs are met. The family caregiver's need, to be understood, is not.

The system collects what it needs.

It never asks the harder question: What if the family caregiver is doing everything right in a situation designed to make success nearly impossible?

The experience is hard. Not because family caregivers fail but because the systems around them fail them — over and over and over. The fragmented providers. The insurance authorizations. The constant turnover within organizations and staff. The family dynamics. The financial decisions. The legal documents. The 19 Caregiving Systems™ were never designed to be navigated by one person without a billing code.

The research looked at family caregivers and saw burden. It should have looked at the systems and seen failure.

It's not caregiver burden. It's systems burden.

We built something different.

A burden tool tells a family caregiver how hard it is. Our tools ask what they're doing, what it's worth, and who they are while they do it.

A burden scale turns their answers into a score, then sorts the score into a zone, from little burden to severe. Like a signal at an intersection, it can only tell them to go, slow down or stop. And when the light turns red, family caregivers have to drive through it anyway. The systems don't let them stop.

We believe our calculator is the mirror that reflects the value that family caregivers drive for the systems.

The Non-Reimbursed Family Caregiver Savings Calculator has no field for the caree's age. No field for the diagnosis. It asks what the family caregiver does. It tells them what that work is worth.

The answer to the LinkedIn question is: Yes. It is for every family caregiver.

For family caregivers: The research that defined you started from the wrong question. Your experience is the work, not a symptom of someone else's diagnosis. When you connect with anyone who shares caregiving research, including a researcher, ask: How does this research improve my life today? We can add accountability to the field of caregiving research.

For policymakers: Programs funded from burden research inherit its blind spots. Before funding an instrument, ask what the instrument is built to find.

For researchers: A century of repeated burden findings signals a definitional problem, not a data gap. Start from the family caregiver's scope of work.

II. Methodology

How the Calculator Came to Be

I only thought of creating a calculator because I mis-typed a prompt to Claude, the AI tool I use. I wanted Claude to create a chart but actually typed “chat” so it created a chat. Once I saw Claude create a chat in minutes, I realized I could build much more than I ever imagined.

I started with a calculator to show how much an investment in supporting family caregivers returns to a community. I then realized I needed to build a calculator that family caregivers can use to understand their value in their communities and families and within our systems. Over a period of about three days, I prompted Claude with care responsibilities that ultimately became the Nine Caregiving Domains™. I initially added seven domains and later realized I missed two, Assessing and Being.

The Non-Reimbursed Family Caregiver Savings Calculator went live on May 10, 2026. I introduced it in my weekly newsletter, Caregiving Reflections, sent on Sunday mornings. The response was immediate: 383 family caregivers used it in its first 17 days.

The Calculator Experience

Family caregivers select the responsibilities they carry from 53 care types organized into the Nine Caregiving Domains™: Advocating, Assessing, Being, Communicating, Deciding, Managing, Planning, Providing, and Sustaining. They then enter their hours per week and years of caregiving, following the calculator’s instruction: “Caring for more than one person? Estimate the total hours and years for all your carees.” They then indicate whether they live in the United States or outside it, and if this is their first time using the calculator.

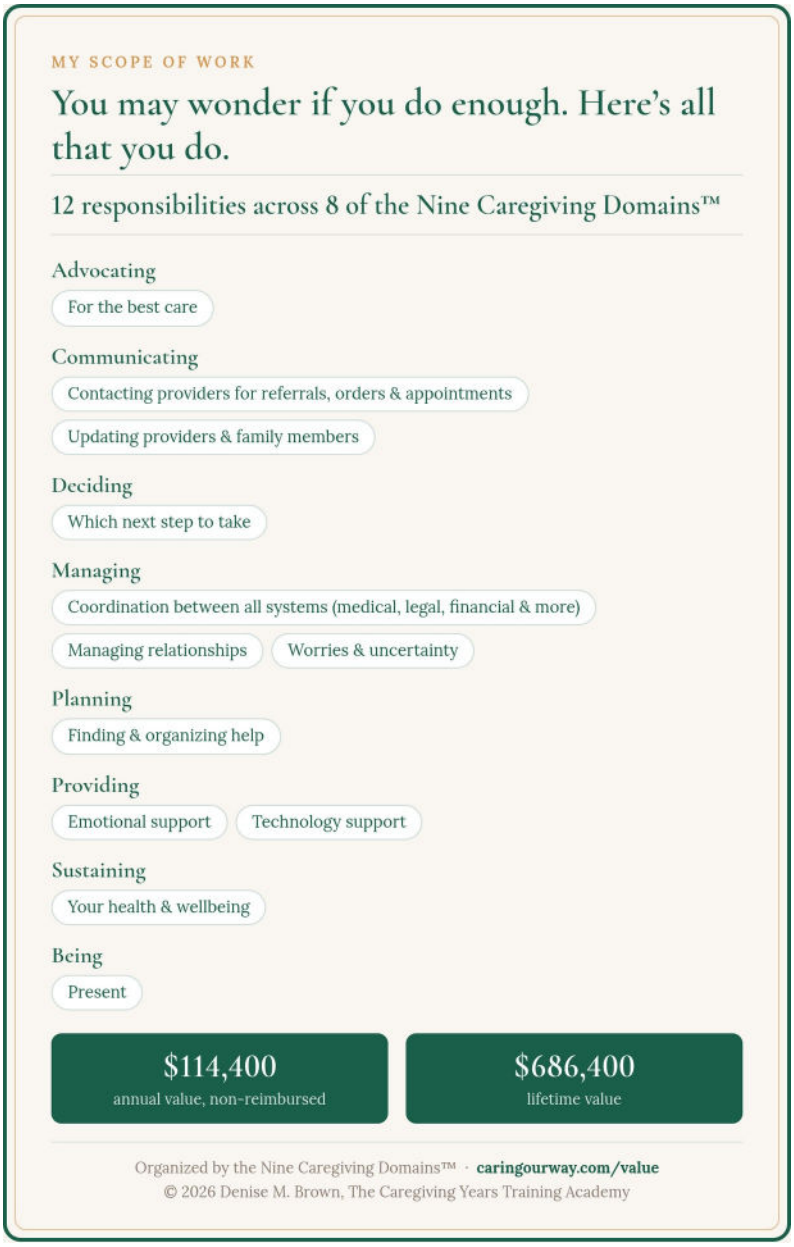
The Nine Caregiving Domains™ are the measurement frame. Task-based instruments start from a list of hands-on activities (bathing, dressing, feeding) or from how the family caregiver feels about their caree. The domains start from the full scope of the work, including the work that has no billing code: managing relationships, living with worry and uncertainty, and sustaining their own life.

Two domains were added after launch. I read a family caregiver’s post on LinkedIn about how much risk assessment happens during caregiving, which prompted me to add Assessing. I then took some time to challenge myself: What else did I miss? I realized I missed Being, the presence we bring to our caregiving experiences. Assessing went live on May 21, 2026 and Being on May 23, 2026. Each domain is measured only from its own live date, so the selection rates for Assessing and Being use only the family caregivers who could have chosen them.

Beginning May 29, 2026, the calculator included an optional question asking family caregivers which domains feel most challenging and which are their wheelhouse. If we understand which domains feel challenging, then we can create programs focused on those domains. In our Certified Caregiving Consultant training program, the CCCs learn how to

personalize support based on each client's wheelhouses and challenges. CCCs also can help their clients determine which responsibilities to delegate. Clients keep their wheelhouses and hand off their challenges.

When a family caregiver finishes, the calculator offers two cards to download. One shows the value of their work. The other lists every responsibility they selected, organized by the Nine Caregiving Domains™. Family caregivers regularly tell me they worry whether they are doing enough, so that card opens with an answer: "You may wonder if you do enough. Here's all that you do."



(Figure 1. Sample scope of work card.)

How the Value Is Calculated

Each care type is matched to the hourly market rate of a professional who does that work. The calculator determines the family caregiver's value by multiplying the highest market rate and their total number of hours.

For 80.8% of family caregivers, that rate is $55 an hour, the market rate for a care systems integrator. Rates applied range from $22 to $55 an hour, with an average of $53.05. For the coordination work family caregivers do most, the $55 rate is conservative. It sits below the national median wage for medical and health services managers, $59.55 an hour (U.S. Bureau of Labor Statistics, May 2025), the federal occupation closest to coordinating care across systems. It is higher than what families pay an aide for hands-on hours, and lower than what they pay a care manager. Section VI prices out the team it would take to replace a family caregiver.

- **Annual value** = hourly rate × hours per week × 52 weeks.
- **Lifetime value** = annual value × years caregiving.

The rate is wages only. It includes no benefits, paid time off, overtime, or holiday pay. Every response, including those from outside the United States, is valued in U.S. dollars at U.S. market rates. Section IV explains why we use one skill-based rate rather than the task-by-task tiers used by AARP and RAND.

Who Responded

This is a voluntary, self-selected sample. Family caregivers found the calculator through my newsletter, LinkedIn, Substack, and word of mouth. We collected this data without a grant, without funding, and without asking a single question about the caree.

- 627 total submissions from May 10 through October 3, 2026.
- 590 unique responses after deduplication (see below).
- 376 in the United States (63.7%) and 214 outside the United States (36.3%).
- 527 first-time, 38 returning, and 25 not specified.

Participation was heaviest at launch: 413 of the 590 responses (70%) came in May.

Family Caregivers' Reactions

When I built the calculator, I thought of family caregivers coming to this tool, using it and then feeling the comfort of the tool truly seeing their work. I wanted family caregivers to enjoy the tool and see it as an ongoing resource to use. I also thought of my caregiving experience, how I spent my time and what needed my time.

After launch, I asked my niece and my younger sister to complete the calculator in my presence. I watched as they read through the selection options, considered the options and then made their selections. I wanted to make sure that the tool made sense to them and that they saw their work in the selections. They each completed the calculator within a few

moments. My niece focused on the calculator without a conversation with me until afterward which led to sharing memories about our work.

My sister spoke as she made her selections: "I did this. You did this. You were better than me at this." I prompted her with a "yes, you did that!" when she wondered if she really had done the work before making a selection. That conversation with my sister was really meaningful for me. She was really stressed out about our parents' declines and deaths so a discussion during caregiving about our reality sometimes was just too much for her. When she completed the calculator, she was calm, reflective. We each shared appreciation for the work the other did. I'm not sure we really did that before.

The calculator has been well-received by family caregivers. Because family caregivers like what the tool does, they share it with other family caregivers. I knew family caregivers would spread the word about this tool if they really found the tool helpful.

Helen, who cares for her husband and cared for her father, shared: "This 'blows me away.' It seems so enormous I cannot comprehend it. What it does help me begin to do is… begin to learn to value my contribution. Thank you for giving me the gift of naming what society has ignored. Thanks for giving us the words!"

Jennifer Richey, who cared for her grandfather and mother, calls the calculator "brilliant." She calculated her value by including all her caregiving experiences, which were consecutive but not concurrent. "We learn so much from our first experience," she explained, "and we bring that expertise to our next one." Jennifer just started caring for her mother-in-law, her next experience.

You can read more comments by visiting our website and our newsletter on Substack.

How We Counted

A calculator is not a survey. Family caregivers use it, look at their number, and sometimes adjust and submit again until the number feels true. Our calculator respects the family caregiver's expertise. The family caregiver knows their experience best so is the best one to define their own experience. We count family caregivers, not submissions.

Same-sitting revisions are collapsed. Since May 28, 2026, each visit to the calculator carries a session token. When a family caregiver submits more than once in the same session, we keep their final submission and count them once. This removed 31 submissions.

Different roles are counted separately. Occasionally a family caregiver submits twice in the same sitting to describe two genuinely different caregiving roles rather than to correct an answer. The clearest sign is that the care selections stay the same while the hours or duration change. We count those as two documented experiences. One family caregiver, whose story appears in Section III, did exactly this: identical selections, two submissions two minutes apart, one for the primary role he held for his parents and one for the coordinating role he holds now.

Submissions before session tokens. Before May 28, the calculator had no session token. For that period, submissions identical in every field (location, first-time or returning, hours,

years and every care selection) within an hour of each other are counted once. This removed six submissions. Otherwise, each submission from that period counts on its own. Some are likely same-sitting revisions with a changed answer; a time-and-location check suggests roughly 37. We count each of them as its own response rather than guess, and we name the limitation here.

Providing only. 17 respondents (2.9%) selected only the Providing domain. That pattern is consistent with direct care workers rather than family caregivers. They are included in every figure. Without them, average annual value would be $176,171 rather than $172,718.

What This Data Can and Cannot Tell Us

It is internally consistent. Across 590 responses, every one of the nine domains was selected by at least 87% of family caregivers. The pattern holds as experience grows: care types rise steadily from 31 in the first year to 42 after 21 or more years, and weekly hours rise from 48 to 102, while domain breadth stays close to the full nine at every stage.

It is self-reported. So are the major national studies of family caregivers, including those by AARP and the National Alliance for Caregiving, YouGov, and KFF. Asking family caregivers directly is the method, not a weakness of it.

It is self-selected, not a probability sample. Family caregivers who chose to use a value calculator may differ from those who didn't. This data does not estimate how many family caregivers there are or how common any experience is across the population. What it shows is the composition of the work: what family caregivers do, across how many domains, for how many hours, and what that work is worth.

It totals the work across all caregiving experiences. The calculator asks, "How many hours a week do you spend caregiving?" and adds, "Caring for more than one person? Estimate the total hours and years for all your carees." That instruction has been in place since launch, and it is by design. Caregiving data often describes one experience at a time. A family caregiver delivers value with every experience, so the calculator shows the whole of the work in one number. The choice has a cost in precision. The question is in the present tense. In my conversations with family caregivers about the calculator, I encouraged them to total previous and present situations. A family caregiver who gave 10 hours a week to one caree and later 30 hours a week to another may have entered 40. For that family caregiver, the weekly total is higher than any single week, and the annual and lifetime values are higher than a year-by-year count would show. We cannot tell how many answered this way. The calculator also does not track how hours changed over time. Lifetime value applies each family caregiver's reported weekly hours to every year of caregiving, so it is an estimate of scale, not an audit. The total is driven by family caregivers who report the most hours over the most years: the 67 who report 168 hours a week account for 36% of it. Where precision matters, we report the median alongside the average. On October 8, 2026, the day this paper was released, we updated the calculator. It now asks family caregivers whether they are calculating one experience or a combination and, for a combination, how many and whether any happened at the same time.

It is large for its field. At 590 responses, the dataset is larger than many peer-reviewed caregiving studies, which often include 100 to 400 participants. It is not comparable to national probability surveys, and we do not present it that way.

How AI Was Used

I am a one-woman show with 10 hours of help each month from a Virtual Assistant. I considered Claude, the AI tool I use, to represent departments I could direct for this project. I directed Claude to develop the tool like I would a team of developers who worked for me. I directed Claude to analyze our submissions like I would with a team of analysts who worked for me. I directed the creation of our white paper like I would with an editorial team who worked for me. The Nine Caregiving Domains™, the care types, and the valuation logic come from my 35 years of work with family caregivers.

I wrote the paper and developed its point of view and its arguments for better caregiving support through reimbursement and interventions for emotional support. Claude ran the analysis, located and checked sources, and drafted some passages, which I reviewed, revised or approved. I was part of every analysis we ran and questioned any number that seemed incorrect. I found errors, directed the corrections and verified the headline figures against the response data. The arguments are mine, and I am responsible for every number and claim in this paper.

For family caregivers: When you use our tool, you name your own work. No one assumed it for you.

For policymakers: This dataset was built without a grant or funding or a team of professionals and reached 590 family caregivers across nine domains and 53 care types.

For researchers: Self-report, self-selected, with transparent counting rules. The claim is about the composition of the work, not population prevalence.

III. Findings

590 family caregivers told us what they do, how long they have done it, and how many hours it takes. Six findings stand out.

1. The Scope of the Role

Family caregivers don't work in one or two areas of caregiving. They work across nearly all of them.

- The average family caregiver selected **34.7 of 53** care responsibilities.
- Among the 252 family caregivers who responded once all nine domains were live, the average was **8.3 of 9** domains. 76.6% selected all nine. 91.7% selected seven or more.
- Family caregivers report an average of 61.4 total hours a week (median 40) and 9.4 total years of caregiving (median 6). These are totals combined across their caregiving experiences, which may not have happened at the same time.
- 67 family caregivers (11.4%) reported 168 hours a week, the equivalent of every hour of every day.
- By their own estimates, these family caregivers have contributed about 21.9 million hours of care across their caregiving experiences. That is an average of about 37,000 hours each and a median of 12,480 hours, the equivalent of six years of full-time work.

Domain	% Selected
Providing	97.3%
Managing	96.3%
Advocating	92.4%
Communicating	90.8%
Sustaining	90.7%
Planning	89.5%
Being (from May 23)	89.3%
Assessing (from May 21)	87.9%
Deciding	87.6%

No domain falls below 87%. The most selected individual responsibilities tell the same story. After emotional support (84.9%), the most common are deciding which next step to take (83.9%), contacting providers for referrals, orders and appointments (83.6%), and updating providers and family members (82.7%). The work family caregivers do most often is coordination, decision-making, and communication, the work between the tasks.

2. Focused on the Few, Missing the Many

Within the Providing domain, the domain closest to what training programs and billing codes already recognize, the gap is widest.

Providing responsibility	% Selected
Emotional support	84.9%
Personal care (bathing, dressing)	58.0%
Medical or nursing tasks	50.0%

The system recognizes and trains for the work of personal care and medical or nursing tasks. That work, though, is done by roughly half of family caregivers. The work it doesn't recognize, emotional support, is done by more than eight in ten.

Other widely shared responsibilities in the Providing domain include companionship and daily tasks (78.6%), transportation (75.9%), medications (75.8%), meals (70.5%), and socialization (69.0%).

The CARE Act and Medicare's caregiver training codes are built around the smaller share. Section V takes up what that means for policy.

3. Technology Support Outranks Personal Care

64.4% of family caregivers provide technology support. **58.0%** provide personal care.

Personal care has training programs, billing codes, and a place in every caregiving study. Technology support has none of these. Yet more family caregivers do it: setting up devices, managing patient portals, troubleshooting telehealth visits, keeping a caree connected.

When I cared for my parents, I spent a lot of time fixing my dad's computer and making sure their iPhones worked. I especially prioritized keeping their iPhones working because they relied on their iPhones to stay connected to news (my dad) and relationships (my mom). Honestly, I both appreciated and cursed the technology. When technology worked, life was easier for all of us. When it didn't, well, we all felt the stress.

When we consider how to support family caregivers, we need to keep in mind that family caregivers become their caree's IT department. A break from that work would be a welcome respite.

4. Worries & Uncertainty

81.4% of family caregivers selected Worries & Uncertainty, one of the responsibilities in the Managing domain. That rate has stayed above 80% across the full dataset.

Worry is not a side effect of the work. It tracks the work. Family caregivers who selected Worries & Uncertainty average **67.3 hours a week** and **$191,281 a year** in value. Those who didn't average 35.5 hours and $91,717.

No billing code exists for worry. No training covers it. And no burden scale asks where it comes from. Family caregivers tell us in their own words that it comes from the systems they navigate: the unanswered calls, the uncertain next step, the decision made without enough information.

5. The Economic Value

Metric	Value
Average annual value	$172,718
Median annual value	$114,400
Average lifetime value	$2,013,860
Median lifetime value	$686,400
Total annual value	$101.9 million
Total documented lifetime value	**$1.19 billion**

The $1 billion milestone was crossed on August 6, 2026, with the 502nd response. Five hundred family caregivers, one billion dollars in non-reimbursed care.

Family caregivers deliver a lifetime of value. It's important that we calculate it.

Family caregivers in the United States report an average annual value of $191,599; those outside the United States, $139,544. Returning users report a higher average ($221,965) than first-time users ($171,765). That may reflect family caregivers who came back once they recognized more of their own work, though the returning group is small (38).

These figures are wages only, and they rest on each family caregiver's own estimate of hours and years. Section II explains what that means for the totals. Section IV explains the rate.

6. The Role Doesn't Onboard. It Arrives.

Years caregiving	n	Avg domains*	Avg care types	Avg hours/week	Avg annual value	Median annual value
1 year or less	52	8.1	30.8	48.1	$135,530	$76,700
2–5 years	225	8.1	31.6	49.9	$139,455	$71,500
6–10 years	148	8.4	35.5	64.0	$181,027	$115,700
11–20 years	105	8.3	38.0	65.8	$183,289	$128,700
21+ years	60	8.8	42.1	101.9	$290,689	$313,170

*Domain averages include only family caregivers who responded once all nine domains were live.

A family caregiver in their first year already works across 8.1 of nine domains, nearly the same breadth as someone caregiving for more than 20 years (8.8). The breadth arrives on day one. What grows with time is the depth: the number of responsibilities within each

domain (31 to 42) and the reported hours (48 to 102 a week). Some of the rise in hours may reflect family caregivers with more years adding together more experiences.

No one trains a family caregiver for this before it begins. No one eases them into it. The scope doesn't grow with experience. It was always that wide.

An Early Signal: Where Family Caregivers Want Help

Fifty-six family caregivers have answered the optional question about which domains feel most challenging and which are their wheelhouse. The group is small, so this is a direction, not a finding.

Sustaining is named most challenging (62.5%), followed by Managing (50.0%) and Being (48.2%). Sustaining and Being are the two domains entirely about family caregivers themselves. Assessing is named least often (19.6%), followed by Advocating, Communicating, and Planning (28.6% each). Of the 54 who named a wheelhouse, most often it is Managing (64.8%), Communicating (64.8%), and Providing (61.1%).

Family caregivers tell us they are skilled at the work that serves everyone else, and that the work of sustaining themselves is hardest. Section V returns to this.

Case Study: One Family Caregiver, Two Roles, One Instrument

Tim Otis used the calculator twice, two minutes apart. He based one submission on his previous role as a primary family caregiver for his mother and father: 25 hours a week, $71,500 a year, non-reimbursed. He based the other on his current caregiving situation: five hours a week, $14,300 a year. A friend now lives with his father and helps with driving to appointments and cleaning. His oldest sister serves as power of attorney, with Otis as secondary.

When comparing the two submissions, we noticed that the work itself didn't change. Both submissions selected the same responsibilities across the Nine Caregiving Domains™, including Managing relationships, Managing conflicts and disputes, and Sustaining relationships. Otis's caregiving now takes fewer hours, and that work is more visible to him. That's what changed.

"I never thought that was part of caregiving," Otis said of the coordinating role he plays now, which includes talking with his father each week and relaying updates to his sisters. The siblings live far apart, and some relational strain among them means Otis serves as the messenger for the whole family. He estimates the work at about five hours a week, or roughly 20 hours a month, much of it navigating that strain. "There's no emotional weight associated with the task," he said of his earlier, more hands-on caregiving. "But when you have the input of your family members involved… that creates a level of strain that, to me, is much heavier than some of these logistical tasks."

Both submissions included his relationship work. When the hands-on hours fell away, it became the work he noticed most.

For family caregivers: Most family caregivers work across nearly all nine domains, and the work done most often, emotional support, is the work least recognized.

For policymakers: Current training codes and the CARE Act address a smaller share of the work than family caregivers actually do.

For researchers: Emotional support (84.9%) and technology support (64.4%) outrank personal care (58.0%). Instruments built on hands-on tasks miss most of the work.

IV. The Reframe: Non-Reimbursed, Not Unpaid

The Turn from Solution to Threat

For years, the Medicaid system saw family caregivers as solutions.

From 1998 to 2004, the Cash and Counseling demonstration gave Medicaid participants in Arkansas, Florida and New Jersey a monthly allowance to hire the help they chose, including family members. More than half of participants in each state said the program improved their lives a great deal. Their family caregivers reported significantly less physical, emotional and financial stress. Nursing home use dropped 18% in Arkansas. Twelve more states adopted the model, and Congress wrote it into law in 2005.

The program soon also solved another problem: the lack of direct care workers. A Medicaid participant didn't have to go without because the state didn't have a direct care worker available to provide care. Instead, the participant could hire a family member.

The program then solved another problem: family caregivers having to be at two workplaces at once. Family caregivers could choose one workplace – the place where caregiving happened – and receive a paycheck. Many no longer had to work another job because, finally, they got paid for their most intense job: caregiving.

And, then, the unthinkable, at least in my mind, happened in 2026.

The solutions somehow became a threat. Family caregivers who save the systems money and keep the systems running became a fraud risk.

In an April 16, 2026, congressional hearing, Robert F. Kennedy Jr., now leading the nation's health apparatus, said Medicaid pays family members to perform basic tasks they once did for free through programs he called "rife with fraud." He said that "the waivers allow people, family members, who are taking care of an elderly parent, who get paid for balancing the checkbook, for picking up the groceries, for driving somebody to a doctor's appointment."

Several states moved to cut these payments. Maryland proposed lowering what some family caregivers earn from about $47 an hour to under $30. Colorado approved a cap that drops paid hours for parent caregivers from 112 a week to 56. Idaho, Indiana and Missouri introduced proposals of their own.

In May of 2026, NBC News reporter Mike Hixenbaugh profiled family caregivers who receive payments through their state's Medicaid program. Casey Barrett, a single father in Colorado, earned his nursing assistant license and built his entire life around caring for his 14-year-old daughter, Olivia. His day involves tube feeding, incontinence care, and constant monitoring for seizures and respiratory distress. He logs up to 112 hours a week. Under Colorado's Medicaid home-care program, he earns about $162,000 a year.

When he describes his day, Barrett doesn't talk about runs to the grocery store. He shares the intensity of providing complex care to his daughter. He keeps her alive.

Colorado's new budget cuts cap reimbursable hours at 56 per week, which decreases his income to roughly $70,000 and threatens his ability to keep his mortgage. "*I would welcome anybody to come try. There's no clock-in or clock-out. This is a continuous, nonstop job.*" — Casey Barrett, NBC News, May 2026

Barrett's $162,000 falls between the median ($114,400) and the average ($172,718) annual value family caregivers calculated for themselves with our calculator.

The Language Is Not Accidental

"Informal caregiver." "Unpaid caregiver." The field uses these terms, appearing in research papers, policy briefs, advocacy materials, and legislative testimony. They call family caregivers "burdened" and "invisible."

They are also wrong.

We are not informal. Informal implies casual, occasional, unstructured. According to our data, family caregivers report an average of 61.4 total hours a week across all their experiences. They work across 34.7 distinct care types. They provide care that keeps people out of hospitals, nursing homes, and emergency rooms. There is nothing informal about it.

We are not invisible. We are interesting, multi-dimensional humans with a passion for quality of life. We show up within the systems all the time, in the emergency rooms, the hospital rooms, the doctors' offices. The systems interact with us regularly because we're the ones making phone calls to fix errors in medical records, fight with payers who incorrectly deny services, and chase down orders so our caree can receive needed services, like hospice care.

In its 2025 report, Caregiving in the US, AARP and the National Alliance for Caregiving describe family caregivers as invisible three times. All three instances appear in its opening pages. Then their definition follows, which overlooks a large population of family caregivers. They named the invisibility three times. Then wrote the definition that causes it.

We are not burdened family caregivers. We are burdened by the systems.

We are not unpaid. Unpaid implies that payment is simply absent: an oversight, a gap, a policy not yet written. The reality is more precise than that.

We are non-reimbursed family caregivers.

Every other system that touches our caree receives reimbursement for its work. The hospital. The physician. The pharmacy. The home health agency. The managed care plan. The social worker. The physical therapist. Each of them bills. Each of them collects. Each of them has a billing code.

Family caregivers are the only system without a billing code while doing the work that makes every other system possible.

The federal government's own count shows it. In September 2026, the Government Accountability Office valued family caregiving at aide wages, inside a category it called unpaid household work. Section VI explains what that choice costs.

That is not informal. That is structural exclusion from the reimbursement system. The language that calls it "unpaid" makes that exclusion sound incidental. It is not incidental.

How we talk about family caregivers matters. When we talk about their work as being an integral part of the system, then we put family caregivers in the system. It's easy to then ask: Where's their reimbursement rate?

If we put the work of family caregivers in the household category, then we make it easy to compare the work of family caregivers with cooking and cleaning. That's not the work of the family caregiver. The threat to their payments through a Medicaid program makes this positioning more important than ever.

Where's Our Hero Pay?

Language matters. The organizations in this field use catch phrases for family caregivers like "Hidden Heroes." If we are these heroes doing this important work, what's our hero pay?

The AARP Public Policy Institute's "Valuing the Invaluable" report, which draws on the survey AARP conducts with the National Alliance for Caregiving, released its newest update in March 2026. It values a family caregiver's hour at $20.41 on average, adjusted by state: $14.12 an hour in Louisiana, $27.05 in Washington. And the rate now depends on the task you're doing. Helping with finances or meals gets one rate. Helping someone bathe or dress gets another. Medical and nursing tasks get a third, higher rate.

RAND, in research commissioned by the Elizabeth Dole Foundation for family caregivers of service members and veterans, takes the same approach. Its floor tier is pegged to minimum wage, state by state. In roughly 20 states, that floor is still the federal minimum wage: $7.25 an hour. Its highest tier is a registered nurse's wage.

Both AARP and RAND make the same mistake. Visiting nurses don't get docked to home-health-aide pay because they spent 20 minutes helping someone get dressed instead of giving an injection. Their rate reflects their skill, full stop, and not which specific task completes within any given hour.

Family caregivers operate the same way. They never do "low-skill" work, even when the task looks simple, because they're the only one in the room who can read what's actually happening, decide what matters, and adjust in real time. Their skill makes complicated tasks look easier to anyone else watching them.

AARP and the National Alliance for Caregiving advocate for a caregiver tax credit, paid family leave and Medicaid home and community-based services (AARP, 2026; National Alliance for Caregiving, 2026). None of these reimburses a family caregiver for the full scope of their work, at a rate that reflects their skill.

Family Caregivers Always Operate at Their Highest Skill Level

That's why our calculator uses one flat rate for everything, everywhere. For most family caregivers, that rate is $55 an hour, the market rate for a care systems integrator. Section II explains how the rate is applied. The rate is wages only: no benefits, no paid vacation, no overtime pay, no holiday pay. Family caregivers don't get those either.

The Value of the Valuers

Organizations that advocate for family caregivers commission or contribute to the research that values their work. That research sets a family caregiver's hour at $20.41 on average, from $14.12 to $27.05 depending on the state (AARP), with tiers that can start at the federal minimum wage of $7.25 (RAND). When we looked at the salaries of leaders in our space, we found they earn about $94 to $161 an hour (Brown, 2026).

The researchers building instruments and receiving funding to research family caregivers aren't valued at $20 an hour either. Sociologists working at grantmaking and advocacy organizations, like the ones producing these reports, earn a median of $135,070 a year, about $65 an hour (U.S. Bureau of Labor Statistics, May 2025).

Leaders in our space deserve to be paid a fair-market rate for running organizations with large budgets and real responsibility. Yet the rate their research assigns family caregivers doesn't reflect the size or responsibility of the enterprises those family caregivers run.

Every Hour Is Valuable

In September 2026, Genworth introduced a benefit that lets long-term care insurance policyholders use benefits to pay their family caregiver. It's real progress: a private insurer now pays family caregivers. But look at the rate. Genworth pays up to 75% of the median hourly cost of non-medical care. Once again, the family caregiver's hour is priced by the task, not the skill, and at a discount to the professional doing the same work.

Every one of the leaders above gets paid one rate. Nobody docks their hourly pay because Tuesday's tasks looked easier than Monday's. Their compensation reflects who they are and what they're capable of, not a task-by-task audit of their calendar.

I don't think the answer is a range, and I don't think it's their zip code either.

A non-reimbursed family caregiver's hour isn't worth a different number depending on whether they fill a pill organizer, manage a feeding tube, find consensus with disputing family members, or advocate effectively to overturn an insurance denial. It isn't worth a different number depending on which state they live in, either. It's worth what their skill is worth, full stop.

Family caregivers are the CEOs of their caregiving experience. CEOs don't get paid by the task and they don't get a pay cut for living in the wrong state.

For family caregivers: You are not unpaid or informal. You are non-reimbursed, and your hour is worth your skill, not your task.

For policymakers: How we position family caregivers impacts how we support them. Family caregivers are part of the 19 Caregiving Systems™. They deserve a reimbursement rate just like every other system.

For researchers: Task-tiered valuation (AARP, RAND, GAO, and now Genworth) produces lower numbers than a skill-based flat rate. The method is a choice with policy consequences.

V. The Three-Part Policy Platform

In 2014, AARP first developed the CARE Act as model legislation, and lobbying for it began that same year, state by state.

The lobbying has been effective. The CARE Act is now law in more than 40 states. Before a patient goes home, the law requires a hospital to identify a family caregiver and offer that family caregiver live training on the aftercare tasks, like how to change a dressing, manage a medication schedule, and operate equipment. Medicare followed in January 2024 with its own billing codes, paying physicians and therapists to train family caregivers in behavior management and daily functional tasks.

Both are real progress. Both misunderstand the family caregiver's real work.

The CARE Act and Medicare's billing codes address the work done in the Providing domain. As Section III shows, family caregivers select emotional support far more often than personal care.

The CARE Act Impact

We don't have to guess whether this focus on task training moves the needle for family caregivers.

A 2022 study out of the University of Pittsburgh Medical Center followed 2,591 older adults with diabetes discharged under Pennsylvania's CARE Act. It found a gap most people don't expect: only 22.2% of the family caregivers identified under the law actually received the training it requires. Identification and training are two different steps, and most families never got past the first one.

For the family caregivers who did receive training, the raw numbers looked better: lower readmission and ED-visit rates. But once researchers adjusted for how sick the patients actually were, that effect stopped being statistically significant. Identification alone, the CARE Act's first and most commonly completed step, doesn't by itself improve outcomes.

The CARE Act was designed for the hospital and built around a single discharge event. A family caregiver may experience 10 or more hospitalizations over a decade of caregiving. That might amount to 50 days inside a hospital system that finally has their name on file. The law has no impact on the other 3,600 caregiving days.

The CARE Act also requires hospitals to "consult with and provide a discharge plan to the caregiver that includes the aftercare that the patient will require."

Where's the aftercare plan for the family caregiver? A hospitalization is often a crisis for the family caregiver, who saw a medical event happening at home and then made the decision to call 911. The medical event may have been traumatizing. The advocacy required during a hospitalization so a caree receives effective care may have been exhausting.

A family caregiver needs post-crisis care.

What would an aftercare plan for the family caregiver look like? It starts at admission, not discharge. We developed a one-page checklist a nurse can hand family caregivers at the time of their caree's admission (see the Appendix). It lists the kinds of help they might want, from a caregiving coach and system navigation to respite, peer support, palliative care and hospice. They check the referrals they'd like to receive.

The checklist asks them what they need. Something went wrong which led to their caree's hospitalization, and they know the problem because they live it. By discharge day, when everyone is short on time, their referrals are already in motion. We want the discharge plan to include a referral for them: coaching once they're home. Connecting with a professional caregiving coach after discharge gives them compassion as they recover from the hospitalization and support to adjust to another new normal.

We also looked for what this decade-long, 40-state CARE Act campaign cost to run. We couldn't find a consolidated figure, so no one can calculate its return on investment. If the standard is "prove it works before you fund it," the CARE Act never had to meet that standard.

What Task Training Missed

I know this from my own experience. My dad had surgery to remove his bladder and kidney after his bladder cancer had spread. The hospital trained my mom and me on one way to change his bag. The training happened in a small semi-private hospital room while my dad's roommate socialized with visitors on the other side of the privacy curtain.

My mom turned a shade of pale I had never seen before or since. The sight of my dad's wound caused her to sit down. I thought she would pass out. The nurse barely acknowledged my mom's distress. While my mom sat in a corner in that crowded space, I used my iPad to tape the training so we'd have a reference once we got home.

But the video never helped.

Everything was different once we returned home. The healing wound looked different. A few days after arriving home, we couldn't tell whether my dad's ostomy bag was leaking. He spent a night sitting up in his recliner, waiting, until a visiting nurse arrived the next morning. That visiting nurse gave us completely different instructions than we'd been given in the hospital.

My experience is not unique. I recently connected with a family caregiver who received about 10 minutes of training to manage her husband's IV treatments at home. She arrived home, left on her own, to figure it out until the home health nurse's first visit. No one called to check on her and to ask her how she's managing.

Task training, delivered exactly as the law requires, failed. We need training where we provide care. We also need more than training, because so many of us provide more than hands-on care. My mom needed emotional support after my dad's hospitalization. I provided that. The ostomy nurse never checked on my mom, my sister or me, his primary

family caregivers, to make sure we felt comfortable providing the care he needed until he died eight years later at home.

Training and Coaching Solve Different Problems

A hospital nurse can show a family caregiver how to change a dressing correctly. That's training, and it matters. It cannot show them what to say when their father tells them, mid-task, how much he hates needing this kind of care at all.

When I changed my dad's bag, he always told me how much he hated it. The nurse never told me how to manage those conversations, or how to manage my own emotions in the middle of them.

That's not a skills gap. It's a support gap, and it's the gap we train professionals like a Certified Caregiving Consultant (CCC) to fill. A CCC doesn't replace the wound care instruction or the medication training. A CCC sits in the experience no discharge instruction covers: the fear, the grief, the identity loss a caree works through in the same moment a family caregiver performs a task correctly. Training teaches the hands. Coaching supports everything the hands don't touch but the heart feels.

Coaching is the aftercare for the family caregiver.

Why the Billing Codes May Be Underused

Medicare's new caregiver training codes have seen low uptake so far, and the usual explanation is provider-side: billing friction, unfamiliar codes, lack of awareness. That may be true.

But our data suggests a second, quieter explanation. As Section III shows, family caregivers name Sustaining, Managing and Being as the domains that feel most challenging. If family caregivers need the most help from the domains that sit outside of task instruction, then a code built exclusively around task instruction addresses a smaller share of the actual need. You can't drive utilization of a service by making it easier to bill for something family caregivers didn't say they needed most.

Does It Take Work Off Their Plate?

Now that we understand the family caregiver's scope of work, we can ask one question of any program built to support family caregivers: Does it take work off their plate, or add to it? Many programs add. They teach family caregivers to plan a special diet or to transfer a caree from a wheelchair to a bed. Education is good. But each lesson becomes one more task for someone already working across nearly all nine domains. Taking real work off their plate makes a much bigger impact.

I once consulted with an organization that provides training for family caregivers. They believed that home health aide training, tailored toward family caregivers, met the only need family caregivers have. At one point I had to stop and say to the staff: Everything you're creating is only useful for someone who does nothing but hands-on care. The tips

they wrote meant a family caregiver could only have time in their day for the caree's care. They didn't offer tips on how to keep a life. Family caregivers have a life. They need time for their lives so they keep them.

Coaching meets that test because I take work off a client's load during a coaching call. One client is often overwhelmed by the scope of her work, so we create a list of priorities. I send the list to her after our call, and she feels better following it. When we work through her priorities, I also am lessening the work required to make decisions. Deciding which next step to take is work that 83.9% of family caregivers selected in our calculator. Another client talks out the pressure of her uncertain life — what her day will be like and how long caregiving will last. When she speaks honestly about the stress and worry because of the uncertainty, she shares the weight of that work with me. Every client discusses worries and uncertainty during our calls, and we think through strategies together. Managing worries and uncertainty is work that 81.4% selected. During coaching calls, family caregivers no longer work alone.

Three Achievable Changes

The CARE Act and Medicare's training codes are a real first step toward reaching family caregivers. But right now, training is treated as the only step. We can create meaningful impact starting with what we already have. We do not need a new federal law or a new billing code.

- **Clarify CHI and PIN.** Medicare introduced Community Health Integration and Principal Illness Navigation codes in 2024 that include language authorizing "social and emotional support." Right now, that language is written for the patient. We want CMS to state plainly that the family caregiver, as well as the patient, can receive that same support. We want that support **delivered by an auxiliary professional who completed specialized training to coach and consult with family caregivers**, not simply a navigator whose training is oriented entirely around the patient's condition. Certified Caregiving Consultants, for example, complete 115 hours of specialized training in exactly this work of supporting family caregivers.
- **Open the home health team to coaching.** Medical social services are already one of six disciplines bundled into home health's Part A payment. **A trained auxiliary professional delivering coaching to the family caregiver, billed separately under Part B through CHI or PIN, is new, additional revenue for a home health agency, not a duplicate of a service they already provide.** The physician who already certifies the home health plan of care can serve as the billing practitioner.
- **Add an aftercare plan to CARE Act discharge.** The CARE Act already requires hospitals to notify the family caregiver before discharge. **This same notification should include an aftercare plan for the family caregiver with referrals to support and help for them, including to a caregiving coach, the same way discharge plans already refer families to home health agencies and DME suppliers.** A referral built into the discharge plan starts support once the caree is home, billed under Part B the same way CHI and PIN already are.

Why three asks and not one? The first two involve decisions CMS can make within existing Medicare rules. The third sits in state law, because the CARE Act is enacted state by state, so it goes to state legislatures. Each ask goes to the body that can actually act on it.

The National Alliance for Caregiving has asked CMS to widen who can deliver these services and to lower their billing thresholds. As far as we can find, no one yet is asking CMS to say clearly that the family caregiver can also be the one receiving the support, or to require that the professional delivering that support must be specially trained in the caregiving experience to deliver it. We haven't found anyone advocating for an aftercare plan for the family caregiver either.

A 2026 evaluation I co-authored, published in the *Journal of the American Medical Directors Association*, paired coaches with family caregivers of people with dementia for five sessions. The 16 family caregivers who completed it reported less stress and better well-being and quality of life, and rated the program 4.7 out of 5. It's a small study, and it matches what I've seen in coaching since 2004. My clients tell me so at the end of nearly every session.

We introduced a law and billing codes for training without any evidence of impact. **We can confidently advocate for coaching support; the early evidence and more than 20 years of practice point the same way.**

Family caregivers don't just need to be shown how. They need someone who can sit with them in what the how doesn't cover, like the worries, emotional exhaustion, and grief. Right now, that support has a proven practice behind it and no reimbursement pathway in front of it.

In September 2026, we led an advocacy campaign through our nonprofit, The Caring Board NFP. We encouraged family caregivers and professionals serving family caregivers to submit the first two asks to CMS as a public comment on the CY 2027 Physician Fee Schedule. Our Advocacy Hub tracks what happens next. Beginning October 25, 2026, we will include these three asks in our Certified Caregiving Advocate training program. The program prepares family caregivers to engage with their community leaders and elected officials and ask for what they need.

For family caregivers: Support for you, not only training, can be covered through billing codes that already exist. As you consider programs, services and other kinds of help, ask: What will alleviate responsibilities within my scope of work?

For policymakers: Three achievable changes: clarify CHI and PIN, open home health to coaching, and add an aftercare plan with referrals, including to a caregiving coach, to CARE Act discharge. Ask: How can I support programs and services that provide relief for the family caregiver from their scope of work?

For researchers: The CARE Act spread without outcome evidence; the one real check found no significant readmission benefit after risk adjustment. Ask: How will my research lead to interventions that reduce the family caregiver's scope of work?

VI. Discussion — What the Field Missed

Why This Matters Now

Money is moving toward family caregivers in ways we have not seen before. In November 2025, Texas voters approved $3 billion over 10 years to establish the Dementia Prevention and Research Institute of Texas. In January 2026, Illinois released EngAging Illinois: A Comprehensive Plan for Living Well, a decade-long blueprint through 2036 with an explicit focus area titled "Investing in Caregivers."

In May 2026, the National Alliance for Caregiving filed a public comment with CMS on the proposed 2028 Home and Community-Based Services Quality Measure Set, co-signed by 22 organizations, pointing out that family caregivers are almost entirely absent from the federal measurement framework. Their recommended solution: "validated caregiver burden and support measures."

As money flows, the measurement field is already deciding how it will be spent. And if the field follows the path it has always followed, the instrument already waiting on the shelf is the same one it has used for 46 years.

What the Zarit Burden Interview Actually Asks

The Zarit Burden Interview is the most widely used instrument in family caregiver research. It has shaped 46 years of studies, funding decisions, and program design.

Here are a few of its questions, adapted to use our term, caree, where the instrument says "your relative":

Do you feel your caree is dependent on you?

Do you feel angry when you are around your caree?

Do you feel that your caree currently affects your relationships with other family members or friends in a negative way?

Do you feel uncertain about what to do for your caree?

Some of the questions don't even measure a feeling. They measure a fact, and then score the fact as if it were a symptom.

Take this one: Do you feel your caree is dependent on you? Of course you do. Dependence is not a side effect of caregiving. It is the definition of caregiving. The instrument can't tell the difference between a family caregiver who finds that dependence devastating and one who finds it simply true. Both answers score the same. The scale has no room for "yes, and that's fine."

Then there's this one: Do you feel you should be doing more for your caree? There is no honest answer to that question that isn't guilt. Every family caregiver, no matter how much

they give, can imagine doing more. The question manufactures the feeling of failing, then records that feeling as data.

I wonder about this one: Do you feel that your caree currently affects your relationships with other family members or friends in a negative way? A caree's disease impacts the relationships in a way that's heartbreaking for a family caregiver. Friends stop calling, invitations to social events stop. How does any family caregiver begin to answer this question without feeling the pain of relationships lost because of their friends' discomfort with a caree's disease process?

That's not measurement. That's an instrument built to find burden everywhere it looks because it would find burden in a Tuesday.

The Zarit Burden Interview was developed in 1980. It is still the field's go-to instrument 46 years later. The questions have barely changed. Neither have the findings.

Consider changes during the last four decades that now impact family caregivers. In 1980, family caregivers had no patient portals to manage, no telehealth visits to troubleshoot and no Medicare Advantage plans to navigate. Hospital stays were longer. In 1983, Medicare began paying hospitals a fixed amount for each diagnosis. The average Medicare hospital stay fell 9% the following year, the largest one-year drop the program had seen (Guterman & Dobson, 1986), and more care moved home. Today's shortage of direct care workers had not yet left family caregivers without help to hire. Our calculator shows where the work is now: 64.4% of family caregivers provide technology support, and 83.6% contact providers for referrals, orders and appointments. A scale written for 1980 does not include questions about that work.

The Zarit isn't the only assessment that looks for burden inside the family caregiver. Area Agencies on Aging, including throughout the state of Illinois, use an assessment tool called TCARE (National Academy for State Health Policy, 2025). Research published in 2008 introduced the assessment, which defines caregiver burden as a result of identity discrepancy (Montgomery & Kwak, 2008). In that theory, the gap between what a family caregiver does and who they believe they should be causes the burden. The theory says discrepancy shows up as three types of burden, plus depression:

- Objective burden: the feeling that caregiving is intruding on time, energy, privacy, and other obligations.
- Relationship burden: the feeling that the caree demands more attention than their condition warrants.
- Stress burden: general anxiety and negative emotion tied to caregiving.

Illinois held 24 roundtables in the fall of 2023 to better understand what family caregivers need. More than 400 participants, including family caregivers, asked for more available and affordable respite and a single easy-to-use hub. They named their biggest challenges as financial strain, navigating complex healthcare systems, stress and burnout, and a shortage of direct care workers (Illinois Department on Aging, 2026). They named system stress. They did not name stress related to who they are during caregiving.

The system has its reasons for using TCARE. Washington state began using it in 2010. When the state later opened its family caregiver program to more family caregivers, their carees started using Medicaid long-term care more slowly (Lavelle et al., 2014). For a state, every month a caree stays off Medicaid long-term care is a month it doesn't pay for that care. The evaluation, though, couldn't say whether the assessment or the extra support made the difference.

I've written about completing TCARE and about who family caregiver assessments serve (Brown, 2024, 2026).

I once asked the director of a nonprofit how family caregivers feel about completing that assessment which her program requires. Silence. Then she said, "Well, I'm sure they don't like it. But they need to complete it in order to be approved for help through our programs."

I watched my niece and my sister complete our calculator because I wanted to witness their experience. That critical step, observation, is rarely part of how burden instruments are built or used. We measure family caregivers. We seldom ask how it feels to be measured, or whether they are better off afterward. We are doing something to the family caregiver without understanding what it does. Imagine the impact if family caregivers assessed these tools themselves and selected the ones they want to complete.

The Price of Entry

Most professionals using the Zarit didn't choose it. It was handed to them as the standard, in training programs, research protocols, documentation requirements. Using it feels responsible because everyone else uses it.

A professional who has never been a family caregiver may not feel the weight of being asked to rate anger toward a father. The professional scores it, norms it, files it. The instrument feels clinical and neutral because the professional is on the outside of it.

The family caregiver is on the inside of it.

They need help. So they comply. They probably don't complete the Zarit because they find it useful. They give a number to each question because the program they want to use requires it. The assessment is not offered as support. It is the prerequisite for support. Pay the toll, then maybe we'll let you through the gate.

That is not a measurement problem. That is a power problem. When the family caregiver answers those questions in order to qualify for help, **the burden scale becomes the burden**.

The field calls this evidence-based care. Family caregivers call it the price of entry.

A program director planned to integrate the Zarit 7-item instrument into his organization's impact measurement. He had a genuine question for me: How do you measure relationships? How do you measure "am I still me?"

I told him our Certified Caregiving Consultants use an 8-question assessment that includes this question: "Who and what do you love?" You can follow up that question with: "How often do you spend time with who and what you love?" When they spend more time with who and what they love, they are themselves. That's worth measuring.

Two questions. Not twenty-two. And neither one asks the family caregiver to rate anything about the caree.

The Scale Assumes the Source

In June 2026, a family caregiver sent me a note because he took the Zarit and scored a 68, which landed him in what the instrument calls the burnout zone. "No surprise," he wrote. He cares for his spouse 24 hours a day.

A spouse caregiving 24 hours a day and scoring high on a burnout scale isn't a finding. It's a confirmation of something everyone already knew. The scale does serve one purpose: a high score might trigger more help. But the number cannot tell anyone what kind of help he actually needs. Does he need respite? Someone to talk to? Help navigating a benefits system? It's the difference between a diagnosis and a direction.

Glenna Crooks, a health policy strategist, asked: "Why is it only about feelings?" She's right. Every question in that instrument circles back to the same assumed source of burden: the caree. The scale decided, before you answered a single item, that the source of your burden is only your caree.

But I wasn't burdened by my parents. Okay, my dad challenged my patience. I loved taking care of my mom, though. I miss taking care of her.

I was burdened by my older sister, who turned every decision into a battle. I was burdened by my parents' physician whose disorganized, ineffective practice I endured because my parents chose him and stuck with him. I was burdened by the grief of my brother's death, which happened one year before my mom died and two years before my dad died. I was burdened by fax machines because orders must be faxed and providers must review their faxes before services will start. I was burdened by systems (payer, medical, community) that I never chose to navigate and couldn't opt out of.

None of that shows up on the Zarit. It can't.

Sharon Anderson, a researcher in aging and family gerontology, shared two recent academic papers that try to improve on the Zarit by asking the caree, not just the family caregiver, to rate burden. Anderson asked the right question: Have we moved beyond the burden paradigm or have we simply made it dyadic?

I read both papers. The answer is the second one. The caree now rates how much they feel they burden the family caregiver. The family caregiver still rates their own burden. Two people, same assumption: if there's burden during caregiving, it resides within the family caregiver-caree relationship. Neither version has a place for my sister, the physician, the grief, the fax machines. I also can't imagine my mom or dad answering questions about how much of a burden they feel they are on me.

Forty-six years of trying to fix the instrument have produced refinement after refinement that still can't imagine burden coming from anywhere else.

> **For family caregivers**
>
> If you reach out for help through your local Area Agency on Aging, you may complete a burden assessment. TCARE and the Zarit Burden Interview are two that are used. If you want to enroll your caree who has dementia in Medicare's GUIDE program, you complete the Zarit too. None of these tools seem to ask about the burden you carry because the systems are siloed, short-staffed, disorganized and difficult to navigate. None ask what kind of support you would like to receive. If you don't feel stress within your relationship with your caree, the Interview may assume your burden is low. In the GUIDE model, if you score low, you may not qualify for more support and for respite.

They Almost Become the Diagnosis

When I first developed the Six Caregiving Stages™, I tried to tie a family caregiver's progression along the stages to the caree's disease progression. It was a nightmare. I also tried anchoring the stages to where the caree lives. That didn't work either.

The concept became clear only when I let go of the caree entirely. When I stopped asking about the caree and started completely focusing on the family caregiver, the concept just bloomed for me. For the family caregiver, the experience is all about the emotions.

Thirty years later, the field still makes the mistake I almost made.

Our space often prioritizes organizing family caregivers by the caree's diagnosis. The husband watching his wife's cognition shift slowly, without a label yet attached, doesn't fit the framework for services. And the family caregivers who do qualify don't access support as themselves. They access it as an appendage of the diagnosis. The Alzheimer's caregiver. The cancer caregiver. The ALS caregiver.

Not a person. A category derived from someone else's condition.

Several years ago, a family caregiver asked me to connect her to another spouse caring for a husband with stage 3 colon cancer. I invited her to join a chat happening in my online community. She immediately connected with another family caregiver. The two connected because they once traveled extensively in their RVs. Because of caregiving, they stopped traveling. They talked about their RVs, taking their last trip, selling them. They never spoke about their spouses' diagnoses: cancer and dementia.

We connect over impact because impact affects our lives.

We don't organize parents by the gender or ages of their child. Parents gather. They connect over the experience of parenting. We need to create the same experience for family caregivers, and then let them choose their own peer support, whether that's

someone whose caree shares the same diagnosis, someone in the same workplace, or someone raising young kids while caring for a family member.

A New Instrument for Every Circumstance

A team of researchers is building a brand-new instrument because their existing one didn't work for long-distance family caregivers. When they gave long-distance family caregivers the Zarit Burden Interview-12 and similar scales, family caregivers said plainly that some questions didn't describe their experience. So the team built a **difficulty index** tailored specifically to long-distance family caregivers of people with dementia.

That's real methodological work. It's also the same paradigm wearing a new label. Burden became "difficulty." Nobody stepped back to ask about the family caregiver's actual scope of work. They measured the difficulty of a job nobody defined.

Once burden requires one scale, dyadic burden requires a second, and long-distance burden requires a third, somebody in an organization needs to figure out which instrument applies to which family caregiver before any actual support can start. That's a new task, invented by the field, and handed to a system that's supposed to reduce the family caregiver's load rather than add to it.

This isn't hypothetical. A systematic review of caregiver burden research in just one condition, kidney failure, found 21 different instruments in use across 24 studies. Nine were built specifically for kidney failure. The other twelve were borrowed from other populations, including three versions of the Zarit, a depression inventory and a fatigue scale. A field with one clear definition doesn't need 21 instruments, and it doesn't need to borrow a depression scale to measure burden.

The review also shows where the definition went wrong. It excluded any instrument that measured only "tasks performed" or "hours of care," because burden was defined as the "perceived negative impact" of providing care. The work itself was ruled out before the review began. The review rated the quality of evidence as low to very low for most of the properties it checked, and no study tested whether any instrument detects change over time.

None of these talk to each other because none of them were built from the same starting definition. How much was spent to develop 21 instruments? We can't know but we know development of those instruments required funding.

With one tool, built from one accurate question, you get a single, complete, comparable dataset across every family caregiver, regardless of distance, diagnosis, or relationship. With a dozen tools, you get a dozen fragments.

The Nine Caregiving Domains™ don't fracture by circumstance because they weren't built from circumstance in the first place. I built them from the work itself. A daughter managing her mother's care from six states away and a spouse sitting in the next room both operate somewhere across all nine. Distance changes which domains reflect more of the work. It doesn't remove any of them. Parents of medically fragile children, spouses, and adult

children all completed the calculator built from these nine domains, and each reached out separately to say the same thing: They saw themselves and their work.

Counted Inside Someone Else's Average

The research that does value family caregivers works at the population level. AARP's Valuing the Invaluable 2026 puts the figure at $1.01 trillion; Otsuka's America's Unseen Workforce, at $873.5 billion. Both multiply hours by a market rate and total them. Neither defines what the work is made of, only its size. The major valuations of family caregiving describe a single year or a single day. None totals what one family caregiver has given across their lifetime.

Our calculator works at the individual level. A family caregiver sees their own number, built from their own responsibilities across the Nine Caregiving Domains™, not their share of someone else's aggregate. The field researched family caregivers for a century. No one built the instrument that lets a family caregiver claim their own value, rather than being counted inside someone else's average.

The Federal Count: What GAO Measured, and How It Priced Us

When Senator Gillibrand asked the Government Accountability Office to put a number on unpaid household work, the result was an important step. A federal agency said, on the record, that this work has economic value and that policy should account for it. GAO also did something the field often doesn't: it separated caregiving from chores. Caring for adults, caring for children and domestic tasks each get their own category and their own wage.

Then GAO priced caring for adults as direct care work. It used the wages of a personal care aide ($17.25 an hour) and a nursing assistant ($19 an hour). The category improved. The comparator didn't.

Family caregivers are not direct care workers. A direct care worker arrives for a shift, completes the tasks in a care plan and goes home. A family caregiver organizes the care plan, coordinates across systems and is still on call at 2 a.m. That family caregiver is doing the work the health care, insurance and social service systems delegated. Every other system that does this work has a reimbursement rate. GAO measured the tasks. It didn't measure the job.

The hours are the same. The job title is not. By GAO's count, adults who care for adults spend an average of 3.15 hours on a typical day, valued at $51 to $64. The same 3.15 hours at the $55-an-hour care systems integrator rate our calculator uses comes to about $173 a day.

GAO's wage choice is a judgment about quality. GAO explains that its "choices of wages also adjust for work quality because they reflect occupations requiring differing skill levels." In its methodology, it goes further: because paid professionals' work "may be higher" in quality than work done by people who aren't professionals, "using professional wages to value unpaid household work may overstate its value." That assumption holds

only if the work is aide work. The responsibilities family caregivers name most often in our calculator are emotional support, deciding which next step to take, and contacting providers for referrals, orders and appointments, as Section III shows. That is coordination and systems work. No one assumes a hospital case manager does lower-quality work than an aide.

What a one-day time diary can't see. GAO relies on the American Time Use Survey, which records a single diary day. By GAO's own account, the survey "generally does not capture activities respondents may routinely do that did not fall on their diary day." About 6.2% of people cared for an adult on their diary day. Counting everyone the survey flags as providing eldercare more than once in the prior three to four months raises that to 16%. GAO also cautions that its daily hours reflect only people who provided care that day and "should not be extrapolated to longer time periods." Worrying, deciding, advocating and being on call rarely show up as timed activities at all. Family caregivers who used our calculator report an average of 61.4 total hours a week across their caregiving experiences.

A *note on comparisons.* GAO's $1.1 to $1.4 trillion for caregiving combines caring for adults with caring for children, so it is not directly comparable to AARP's $1.01 trillion, which covers adult family caregiving only. GAO's finding that women and men who care for adults spend similar time doing it (about 3.17 and 3.11 hours a day) describes time per person, not who family caregivers are.

Source: U.S. Government Accountability Office, *Unpaid Household Work: Estimated Value and Time Spent on Domestic Tasks and Caregiving*, GAO-26-107871, September 17, 2026.

Who Would It Take to Replace a Family Caregiver?

GAO's method, like AARP's, asks a simple question: if the family caregiver didn't do this work, who would you hire to do it?

Family caregivers have no single answer. No one professional does what they do.

If they stopped tomorrow, their carees would need an aide for the hands-on care. They would need a care manager to coordinate providers, schedule appointments and chase referrals. They would need a patient advocate to question the discharge plan and appeal the insurance denial. They would need a navigator for Medicaid, Medicare and the benefits in between. Someone would need to keep three siblings informed. Someone would need to make decisions when the doctor calls with two options and 10 minutes to choose. Someone would need to manage the budget. Someone would need to calm the worries and be the comforting presence. And someone would need to be reachable at 2 a.m.

That isn't one hire. It's a team. The family caregiver already does all of those jobs, often in the same hour. Family caregivers work across nearly all nine domains, an average of 8.3 of 9, and they do it from their first year of caregiving.

Backup plans often can be so difficult for a family caregiver to complete. How do you find a team you can afford and like to step in to take over 35 care responsibilities?

It also explains why respite so often falls short. A respite worker covers the Providing hours: someone stays with the caree while the family caregiver steps away. The Managing, Deciding, Advocating and Communicating don't stop. The family caregiver takes the pharmacy's call in the grocery store parking lot. Respite replaces one of the people a family caregiver is. The rest keep working. Is that really respite when the work continues?

And it means no single rate tells the whole story. Our calculator values a family caregiver's hour at $55 for most respondents. The true cost of replacing a family caregiver depends on which of their jobs you are filling, for how many hours, for how many carees, and whether someone has to answer at 2 a.m. GAO's aide wage understates every version of it.

When I cared for my parents, I became the one available to help 24/7. My siblings couldn't because of their own circumstances. I do not regret making myself so available because I couldn't sleep at night if I didn't. But that takes a toll. A caregiving experience is constant. Getting a break is impossible because we would need a 24/7 replacement.

Pricing the Team

When Ron Duke, a family caregiver in Canada, shared his result on LinkedIn, he described the calculator as a tool "to estimate the value of the caregiving you provide, assuming you could hire people for all the services listed in her tool." His number was $300,300 a year. "I was flabbergasted to see the result," he wrote.

So we priced it. Using what families pay today, here is the team it would take to replace three family caregivers.

Family caregiver	Hours a week	The replacement team	Team cost a year	Our calculator	GAO's aide wages
The average family caregiver	61.4	Aide for all hours, plus a care manager (5 hours), patient advocate (2) and benefits navigator (2)	$159,000 to $172,000	$172,718	$55,100 to $60,600
Tim Otis, today	5	Care manager	$26,000 to $37,700	$14,300	$4,485 to $4,940
Ron Duke	105	Aide for all hours, plus the same three professionals	$237,900	$300,300	$94,185 to $103,740

Three family caregivers, three different answers. Otis's work today is coordination and serving as the family's messenger, and a care manager costs about twice our rate to do it. Duke's hours are mostly hands-on, and an aide costs less per hour than $55, though the hours add up. For the average family caregiver, the team costs about what our calculator says. The same holds at the median: at 40 hours a week, the team costs about $120,000 to $133,000 a year, and our calculator's median is $114,400.

None of these teams is reachable at 2 a.m. Covering the rest of the week adds about $3,700 a week at the aide rate. And our calculator asks family caregivers to combine every caregiving role into one number. If Duke's 105 hours cover more than one caree, his family would need more than one aide.

GAO's aide wage comes in lowest every time: about a third of the average team's cost, and less than a fifth of Otis's.

Rates: home care aide $35 an hour, national median (CareScout 2025 Cost of Care Survey); care manager $100 to $145 an hour (American Caregiver Association, via Care.com); patient advocate and benefits navigator $100 an hour, the low end of published ranges (Solace). Professional hours are illustrative. All figures are in U.S. dollars at U.S. rates, as the calculator values every response.

What We Have Not Solved: Family Caregiver-Specific Support During Hospice

Medicare includes the family caregiver as part of the care team in the hospice benefit. Counseling for family members is a covered service, and bereavement support continues for a year after a death. But hospice is paid a flat daily rate, and support for the family caregiver comes out of that rate with no payment of its own. Medicare's manual describes a social worker's help for a family caregiver only as a brief intervention, two or three visits, when that family caregiver stands in the way of the patient's care. Extra social work visits are paid only in the last seven days of life. And once a caree elects hospice, the billing codes in our three asks may no longer apply. We have not solved this. The question now is: how do we pay for coaching for the family caregiver throughout hospice, and after?

Does the current hospice benefit effectively serve family caregivers? I think of a client's experience and mine.

I began coaching a family caregiver in 2023, shortly after her husband's second major stroke. I continued coaching her through two hospice experiences; hospice discontinued services in the winter of 2024 and then restarted services in the fall of 2025 that lasted until his death in May 2026. When hospice discharged her husband in the winter of 2024, my client lost support from the social worker she liked. During the second hospice experience, my client received a visit from a different social worker and then declined any

additional sessions because the social worker, in my client's words, just didn't get it. I continue to coach this now-former family caregiver with monthly check-in calls.

A few days after my mom began hospice services, the social worker called with an immediate request: He needed to see my mom within the next day, which he said Medicare required. It was not convenient for us (my mom was dying and we were providing 24/7 care) and it was not a service my mom wanted. But we complied, sitting in the living room with a social worker who knew nothing about our situation, who simply showed up to check a box.

During my dad's hospice experience, I never connected with a social worker. One did show up unannounced to see my dad, who lived in a retirement community. She was only able to see my dad because my nephew was there to give me a break and to answer the door. My bedbound dad with a fractured pelvis could not have answered her knock on the door.

Each social worker made a visit. The hospice benefit didn't cover what my client and my family needed: ongoing support from someone trained in the caregiving experience.

The Actual Ask

This isn't a pitch to swap one framework for another. Every program serving family caregivers should be able to reach for one assessment that works whether the family caregiver lives next door or across the country, whether the caree has dementia or cancer or no diagnosis category that fits cleanly at all.

The field doesn't need a better difficulty index. It needs to stop building difficulty indices and start asking about the work.

Funding flows to researchers, who research what gets funded. What gets funded may not be what helps family caregivers.

For family caregivers: Tools built around a diagnosis, a distance, or a relationship may not fit you. One tool built from your work does.

For policymakers: Before adopting "validated caregiver burden measures," consider the family caregiver's experience completing the tool. Every new instrument adds a screening step before help begins.

For researchers: Twenty-one instruments for one condition is fragmentation, not rigor. A shared definition of the work would produce comparable data.

VII. Conclusion — The Escalator Problem

We Don't Have a Care Economy

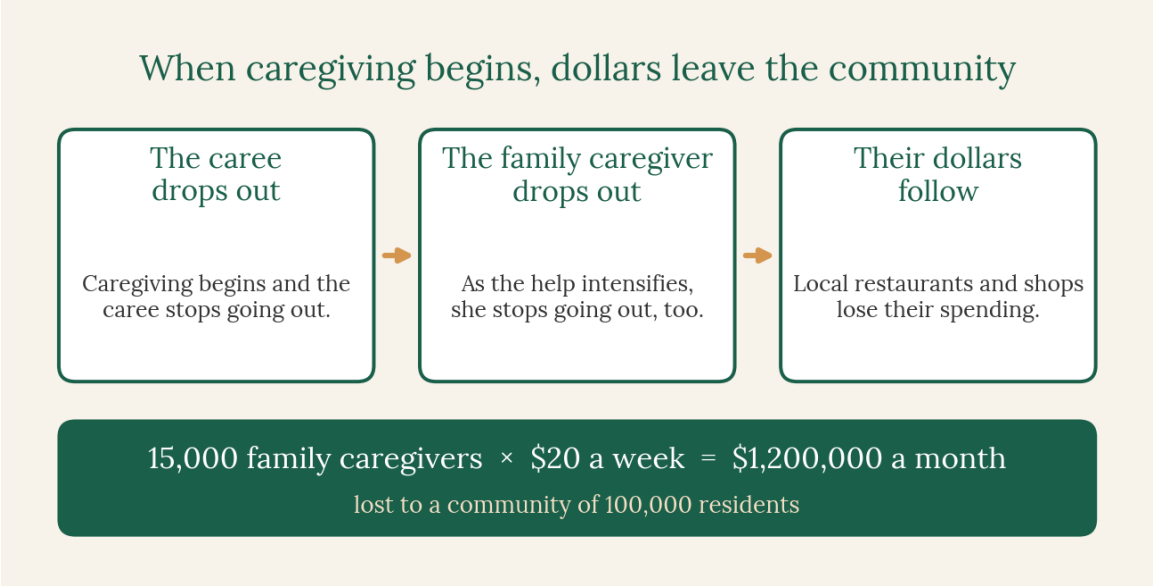
A student in a master's program reached out to me to schedule an interview. She was completing her capstone project on designing programs and services for family caregivers. During our interview, she asked: "How do you define the care economy?"

I love that question. It's a catch phrase for a reality that doesn't exist. We do not take care into account in our economy.

I've been writing and presenting about the impact of caregiving experiences on our communities and economies since 2018. When caregiving begins, our caree drops out of the community. Then, as the help we provide intensifies, we drop out, too. That means we no longer spend money in our communities like we once did.

We fall out of our communities and then our dollars follow.

We have no programs, services or plans in place to bring us back into the community.



(Figure 2. How a caregiving experience pulls spending out of a community. Illustration based on $20 a week in local spending per family caregiver.)

I created a calculator of the price our communities pay when both carees and family caregivers drop out of our communities. In a community of 100,000 residents, perhaps 15,000 navigate a caregiving situation. If each family caregiver once spent just $20 per week visiting local restaurants and shops, and that spending stops, the monthly cost to the community is $1,200,000.

That's why we don't have a care economy. We have an economy. We have a caregiving experience. They could work together to support each other.

Reimbursement is how they start working together. A family caregiver reimbursed for the work the systems delegate can keep a foot in their community: their job, their local shops, their life. The estimated $1.19 billion in work reported by 590 family caregivers in this paper doesn't leave the economy when it's reimbursed. It comes back to the community.

How We Pay for It: The Question We're Working On

I have worked on this question since 2021. That year, I pitched a reporter at The New Republic on paying family caregivers and made it my first priority in conversations with states about new federal funding (Potts, 2021). I also created a planning tool and began hosting a free monthly session to help family caregivers think through a plan for getting paid, whether through a family agreement, Medicaid or Veterans Affairs benefits. A year later, I told The Wall Street Journal, "I think paid family caregivers are the way of the future" (Ansberry, 2022). While attendance at the monthly planning sessions is small, those who attend benefit from talking out a plan.

This paper makes the case for reimbursing family caregivers. It does not yet answer how to fund it. We are working on that question now, and we are naming it openly rather than pretending it is solved. We also are working to demonstrate that reimbursing family caregivers boosts a community's economy.

Hours tell us how large the fund needs to be. In one year, these 590 family caregivers give about 1.9 million hours of care, valued at $101.9 million at the calculator's rates. Across their caregiving experiences, they have given about 21.9 million hours. A state or a program can do the same math for the family caregivers it serves: the hours, multiplied by a rate, are the budget.

What we know is that funding mechanisms for family caregivers already exist. Each one offers a piece of the answer:

- **A dedicated revenue stream.** New Jersey's Statewide Respite Care Program, created by the legislature in 1987, is funded through the state's Casino Revenue Fund. Florida adds $25 to every marriage license and deposits it in the state's Domestic Violence Trust Fund. Pennsylvania's Lottery funds care services for older residents, including care at home.
- **Social insurance.** Washington's WA Cares Fund collects a 0.58% payroll premium and, since July 1, 2026, pays a lifetime benefit of up to $36,500 per person. That benefit can pay a family caregiver, including a spouse.
- **Direct payment.** The VA pays a monthly stipend to family caregivers of eligible veterans. Medicaid self-directed programs pay family caregivers like Casey Barrett. Pennsylvania's Caregiver Support Program reimburses family caregivers up to $600 a month. Genworth now pays long-term care insurance benefits when family members provide care.
- **Public choice.** Texas voters funded the dementia research institute described in Section VI through a constitutional amendment. A state tax-return option could let residents direct funds to reimbursing family caregivers in their own state.

- **Reinvested savings.** When support for family caregivers prevents a readmission or delays a nursing home move, part of those Medicaid and Medicare savings could be returned to the family caregivers who produced them.
- **A research set-aside.** Funders that pay to study family caregivers could require that 10% of each award go to a fund that reimburses family caregivers. In September 2026, the National Institutes of Health (National Institute on Aging) awarded $17.8 million to the University of Illinois Urbana-Champaign to study how caregiving unfolds across the lifespan. A 10% set-aside would be **$1.78 million**. That would reimburse about 10 family caregivers for a full year at the average value our calculator documents ($172,718), or pay for more than 32,000 hours of their work at $55 an hour. The study asks an important question; its lead researcher notes that people may provide care "at several points in their lives, to different people, under very different circumstances." We began asking family caregivers about the whole of their work in May 2026, without funding. A set-aside would let the family caregivers whose experience attracts research funding share in that investment.

The funding must benefit both research and the focus of the research – family caregivers. We can do that when we include a fund to reimburse family caregivers. Money is moving to programs, and family caregivers have told us they want to be reimbursed. A 10% share of Texas's $3 billion, for example, would direct $300 million over 10 years to reimburse family caregivers. A state can build that fund into any initiative it approves or any funding it receives.

Whatever the source, any mechanism that reimburses family caregivers should meet four tests:

1. **It pays for skill, not task.** The rate reflects the family caregiver's role across all nine domains, not the aide wage of whatever task is in front of them.
2. **It follows the family caregiver, not the diagnosis.** Eligibility starts with the work they do, not their caree's condition.
3. **It has a dedicated source.** Reimbursement can't depend on each year's general budget fight.
4. **It grows from day one.** Which brings us to the escalator.

The Escalator Problem

New Jersey got two of these right. Its Statewide Respite Care Program has a dedicated source, and it serves family caregivers of adults with functional impairments rather than one diagnosis. In some counties, it even lets the family caregiver choose the goods or services that help them most.

But in 2014, the state's own Casino Revenue Fund Advisory Commission reported that the program's allocation had not increased since 2002. It sat at $5.3 million a year while the cost of care kept rising. The commission recommended more funding. The statute didn't require it.

A dedicated fund without an escalator slowly shrinks. Any mechanism that reimburses family caregivers must build in an automatic increase from day one, tied to wages, to the cost of care, or to the number of family caregivers served. WA Cares already does this: its benefit adjusts for inflation.

Bringing the Receipts

We began by asking the wrong question: how burdened are family caregivers? This paper asked a different one: what is their work worth?

590 family caregivers answered. They told us they work across nearly all nine domains, and they report an average of 61.4 total hours a week (median 40) and 9.4 total years across their caregiving experiences. They told us the work they do most often is emotional support, deciding the next step, and coordinating across systems that were never designed to be navigated by one person. Together, they reported an estimated $1.19 billion in non-reimbursed work.

One family caregiver showed us why the count matters. Tim Otis spends about five hours a week talking with his father and relaying updates to his sisters, serving as the messenger for a family spread far apart. “I never thought that was part of caregiving,” he told us. He finds that strain much heavier than the logistical tasks he once handled. The definitions that decide who counts as a family caregiver start from tasks and the caree’s condition, and they would likely miss his work. For a long time, so did he. In 2001, AARP found that nearly half of the people doing this work didn’t call themselves caregivers. The hardest work is often the work no one names, including family caregivers themselves. When they can see it, they can name it. When they can name it, they can claim its value.

We are not finished counting. When 1,000 family caregivers have calculated their value, we will seek the opportunity to bring these findings to Congress in testimony.

The system doesn’t have to adopt this for it to matter. But reimbursement is the fix that ends non-reimbursement. Not because we’ve never asked for it, but because we’re the first to bring the receipts.

For family caregivers: Your work has a value, and you can calculate it yourself at caringourway.com/value. Every family caregiver who does makes the next number harder to ignore.

For policymakers: Clarify CHI and PIN, open home health to coaching, and add an aftercare plan with referrals, including to a caregiving coach, to CARE Act discharge. Then build a reimbursement mechanism with a dedicated source and an escalator. In addition, build a reimbursement budget into any funding meant to serve family caregivers.

For researchers and funders: Start from the family caregiver’s scope of work, and work on the funding question with family caregivers, not about them.

Acknowledgments

This paper exists because 590 family caregivers stopped, named their work and put a number on it. Thank you for trusting the calculator with your hours, your years and your responsibilities. Every finding here is yours.

Thank you to the family caregivers who let us tell their stories by name. Tim Otis used the calculator twice to show two roles in one caregiving experience, then reviewed every passage about him so we would get it right. You can connect with Tim through his organization, Empaira, which offers online support for family caregivers. Ron Duke shared his result publicly and described the calculator, in his own words, as a way to price the team it would take to replace a family caregiver.

Thank you to everyone who shared the calculator in newsletters, on LinkedIn and Substack, and by word of mouth, and to the family caregivers who answered "Why Is Caregiving So Hard?" in public, so others could see themselves in their answers.

Thank you to Helen, whose words about the calculator appear in Section II. Thank you to Glenna Crooks and Sharon Anderson, whose questions sharpened the discussion of burden scales in Section VI. Thank you to my niece and my younger sister, who tested the calculator at my side and shared memories of our work together.

Thank you to the Certified Caregiving Consultants, including Jennifer Richey, and the members of Caring Our Way, whose questions and stories shaped the Nine Caregiving Domains™ and every tool built from them.

About the Author

Denise M. Brown is the founder and CEO of The Caregiving Years Training Academy. She began helping individuals who care for a family member in 1990 and launched a business to support them in 1995. She created one of the first online caregiving communities in 1996 and managed it until its sale in 2020. Her current community, CaringOurWay.com, offers support during and after a caregiving experience. Brown began helping her parents in 2004, after her father's bladder cancer diagnosis, and cared for them until her mother's death in 2022 and her father's in 2023. Her brother's unexpected death in 2021 complicated her already complex caregiving and grieving experiences.

Next Avenue named Brown a 2017 Influencer in Aging. She is the author of several books for those who care, including the five-book Take Comfort series, *The Caregiving Guide* and *After Caregiving Ends, A Guide to Beginning Again. In spring 2027, she plans to release Failing Family Caregivers, a book that expands on many of the themes in this paper.*

About the Author's Work

Brown develops and delivers training programs for the workplace and for individuals who want to coach family caregivers, including the Certified Caregiving Consultant program.

More than 700 individuals from eight countries have enrolled in her training programs. She also coaches family caregivers.

Brown also delivers CEU-approved workshops to hospital discharge planners and case managers, educating them about ethics, implicit bias and cultural competency from the family caregiving perspective.

The three changes this paper recommends would create a way to pay for coaching for family caregivers. That change could benefit the professionals Brown trains and her business. Brown is also Executive Director of The Caring Board NFP, the nonprofit that led the public comment campaign described in Section V. No grant or outside funding supported the calculator or this paper.

The Nine Caregiving Domains™ are Brown's proprietary framework. Organizations interested in licensing their use can contact her at denise@careyearsacademy.com.

Over the past 18 months, Brown also provided about 170 hours of coaching at no charge to 13 family caregivers, who range in age from 35 to 94. That work, and her ongoing conversations over the past 30 years with family caregivers about their reality, inform the recommendations in this paper.

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What Would Help You?

Tell us what you need now so we can start organizing referrals for you.

Supporting a family member is hard work. You deserve support. Check what could help.

- ☐ **Caregiving Coach**
  Ongoing support for your worries and stress from a trained professional
- ☐ **Respite & Self-Care**
  Breaks and support to keep your own life going
- ☐ **Peer Support**
  Connecting with other family caregivers who understand
- ☐ **Decisions & Next Steps**
  Help weighing options and choosing what comes next
- ☐ **Family Communication**
  Help updating family and working through disagreements
- ☐ **System Navigation**
  Coordinating providers, referrals and appointments
- ☐ **Crisis Planning**
  Making a plan for the next crisis
- ☐ **Financial & Legal**
  Insurance, benefits, POA and paperwork
- ☐ **Technology Support**
  Devices, patient portals and telehealth
- ☐ **Home Safety**
  Getting the home and equipment ready
- ☐ **Personal & Medical Care**
  Learning medications, wound care or other hands-on tasks
- ☐ **Household & Meals**
  Help with everyday tasks at home
- ☐ **Transportation**
  Rides to appointments and the pharmacy
- ☐ **Palliative Care**
  Comfort-focused care alongside treatment — you can ask for this yourself
- ☐ **Hospice Care**
  End-of-life comfort care — you don't have to wait for a doctor to bring it up
- ☐ **Something else:** _____

Your name: _____ **Best way to reach you:** _____

Caree's name: _____ **Room / Unit:** _____

For the care team: *Use this checklist to include referrals in the discharge plan.*

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