CAREGIVER

RESOURCE GUIDE

NOVEMBER 2026



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Pictured: Rachel's grandma, Barbara, changes her diaper, c. 1986.

Editor's Note

That's my grandma in the photo, changing my diaper. She helped me long before I could do anything for myself, and years later it was my turn to help her. Nobody handed me a manual for that. I learned as I went, and I made plenty of mistakes along the way. Helping her is the reason this guide exists.

Caregiving rarely arrives with a manual. More often it begins with a phone call, a diagnosis, or a slow realization that someone you love needs more from you than they did last year. Then you learn as you go, usually while juggling work, family, and everything else on your plate.

If you picked this up in a quiet moment, maybe between appointments, after a long day, or while someone else is finally keeping watch, we're glad you did. You don't have to read this guide cover to cover. Turn to the topic that matches what you're facing today and set the rest aside for later. Whether you're caring for a parent, a spouse, a child with a disability, a friend, or a neighbor, you'll find a place to start.

This guide is organized by topic. For each one, you can find additional resources on our resource portal at the Sandwiched KC website, including programs and services across the KC metro for caregivers, older adults, and people with disabilities.

Asking for help is not a sign that you're falling short. It's part of what makes caregiving sustainable. We hope this guide helps you take that next step, whatever it is.

With respect and reverence,



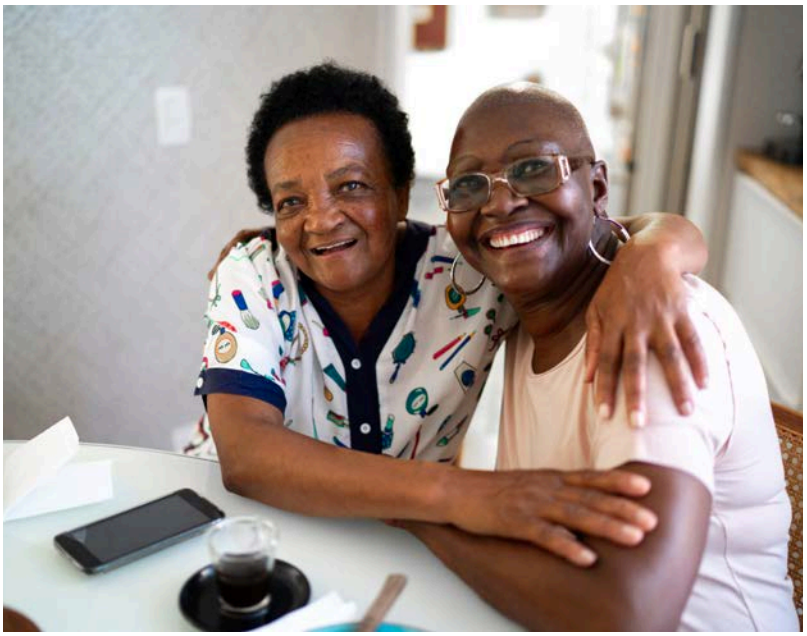
Rachel Hiles, Founder
Sandwiched KC

SHAMELESS PLUG

KC'S FIRST STOP FOR CAREGIVERS







Are you helping a loved one or know someone who is?

According to our calculations, over 500,000 people living in the Kansas City Metro are caring for older parents or loved ones, helping them live independently at home or overseeing their care in the community. Caring for a loved one has its joys and rewards, but it doesn't come without stresses and challenges.

We launched Sandwiched KC in January of 2018 with the vision of welcoming, embracing, consoling, and supporting family caregivers. Our mission is to create opportunities for family caregivers to find local support and shared wisdom.

In addition to our signature virtual support groups (we've been "Zooming" since 2018), we began meeting in person last year to offer even more opportunities for you to connect with your fellow family caregivers.

Looking for 1:1 support? We offer personalized recommendations, resource referrals, and a listening ear.

Call Sandwiched KC today at (816) 472-9178 or visit us online at sandwichedkc.com







SUPPORT GROUPS

There are many benefits to connecting with others who are caring or previously cared for a loved one. Attending a support group has many advantages:

Emotional Support
Support groups offer a safe space to share feelings, frustrations, and experiences and can help reduce feelings of isolation and loneliness.

Practical Advice & Resource Sharing
Support groups create an avenue for us to exchange practical tips and strategies for managing caregiving challenges. In our support group, we help each other find local resources, such as respite, financial aid, and legal assistance, and share recommendations for healthcare providers and other professionals.

Validation
Above all, hearing from your fellow family caregivers tends to confirm that the challenges we face are normal and shared by others. This can be truly life-changing reassurance.

DIAGNOSIS & DISEASE SPECIFIC

When our loved ones have chronic illnesses or cognitive issues, those conditions can create unique challenges that are hard to cope with and understand if you haven't experienced them firsthand. Sometimes, it's helpful to connect with current and former caregivers in support groups focused on your loved one's specific condition.

For a listing of support groups for conditions like Alzheimer's and dementia, cancer, Parkinson's disease, and more, visit our website.

GRIEF & LOSS

After caregiving is over, connecting with others who have also experienced grief and loss may serve as a comfort. Community or faith-based support groups provide a welcoming space to express your feelings and share your experiences. To locate a grief support group near you, visit our website and click on Resources.

Find local support groups at sandwichedkc.com/resources

EACH ONE OF US HAS LIVED THROUGH SOME DEVASTATION, SOME LONELINESS, SOME WEATHER SUPERSTORM OR SPIRITUAL SUPERSTORM... WE MUST SUPPORT EACH OTHER AND EMPATHIZE WITH EACH OTHER BECAUSE EACH OF US IS MORE ALIKE THAN WE ARE UNALIKE. —MAYA ANGELOU

THE THINGS WE DO FOR LOVE

Families are the long-term care system of the United States.

When you think about the term "long-term care," what comes to mind?

If you immediately thought of a nursing home or similar facility, you are not alone.

There are many misconceptions about who cares for people when they require assistance due to aging or a disability.

Long-term care is not a facility. Long-term care is something you create for a person, whether by surrounding them with the support(s) they need to stay where they are, or by moving them to a place where they can have that level of supervision.

Essentially, there are three types of long-term care older adults and people with disabilities can receive at home. No matter which path you take on your search for home care, there are risks and rewards.

Before we begin, we feel we need to explain something. When we say "home care," we are talking about assistance with daily living activities, like meal preparation, light housekeeping, and help with dressing. This is non-medical care. It is not the same as "home health care." Skip to Page 10 for an explanation on the difference between the two.

Types of Long-Term Care

IN-KIND CARE

This is the care that nobody ever talks about, and so we're listing it first. It is the care that we family caregivers provide to our loved ones. Often, we are providing it for free.

According to *Caregiving in the US 2025 Report*, 1 in 4 Americans are now caring for a loved one. Of the estimated 59 million family caregivers providing care for a loved one over 18 years old, 89% of them (or 47.8 million) are providing this care with no reimbursement. They are bathing, dressing, toileting, feeding, helping with mobility, shopping, managing finances, preparing meals, handling transportation, and even handling medical or nursing tasks such as managing catheters, performing injections, or monitoring vital signs.

The problem with relying only on in-kind care is that it often falls solely on one person, and eventually, caregiving can take its toll. The stress and responsibilities of caring for a loved one can result in poor health outcomes and quality of life for those of us who are providing the care. Another risk of relying only on the care of family caregivers is something we all worry about: What if something happens to us? Who will provide the care then?



The Things We Do for Love

(continued)

HOME CARE
When loved ones are no longer able to stay by themselves or live safely on their own due to physical limitations or cognitive issues, finding home care becomes a top priority. Families often seek home care to supplement in-kind care a family caregiver is providing.

Supporting a loved one to receive care in their home often means a higher quality of life and can save money over the ever-increasing costs of moving to senior living options like retirement communities, assisted living or nursing facilities.

FACILITY-BASED CARE
Sometimes it's simply not possible to care for a loved one at home. Whether it's due to intense medical needs, our own health issues, or some other complexity, there are times when we have to help our loved ones find a safe place to live. Even if facility-based care is not you or your loved one's first choice (or even your last choice), it's important to find a place that you can both agree on, just in case.

It's important to do your research and have conversations about long-term care before it becomes a concern-while those we are caring for are still able to contribute to making the decision. 🥪

WHEN YOU SEE A MOVE IN THE FUTURE...

LIVING OPTIONS FOR OLDER ADULTS

INDEPENDENT LIVING
Communities that provide a convenient, senior-friendly environment that may include amenities like meal plans, housekeeping, transportation, recreational activities, and social events, allowing older adults to maintain an active and independent lifestyle.

ASSISTED LIVING
A residential care option for older adults or individuals with disabilities who need some help with daily activities but do not need the intensive medical care provided by a nursing home.

SKILLED NURSING
Skilled nursing is a kind of residential long-term care where people have access to round-the-clock personal and medical care. It is not covered by Medicare but may be (at least partially) covered by Medicaid, long-term care insurance, or private pay.

MEMORY CARE
Memory Care is a kind of residential long-term care for people with Alzheimer's and other forms of dementia. It is not covered by Medicare but may be (at least partially) covered by Medicaid, long-term care insurance, or private pay.

PRACTICAL MATTERS

PROTECTING OUR LOVED ONES: LEGAL CONSIDERATIONS FOR CAREGIVERS & OLDER ADULTS



There is often no limit to what we'll do to protect the ones we love. There are three special considerations when it comes to your caregiving journey.

PROTECTING YOUR LOVED ONE
Our #1 job as caregivers is to ensure the basic safety and security of our loved ones.

That often means educating ourselves on elder abuse protections and rights related to housing, healthcare, and long-term care so we can keep them safe from harm.

PROTECTING YOUR LOVED ONE'S ASSETS
Finances dictate much of our lives, and it is no different when we are in need of long-term care.

It is important to get clear on your loved one's financial situation and consult with legal professionals to find out how you can protect and preserve any assets they may have.

Common legal documents and processes when it comes to your loved one's assets may involve creating wills, trusts, and power of attorney documents to manage their affairs and distribute assets accordingly.

PROTECTING YOUR LOVED ONE'S WISHES
It's a tough conversation, and it's one we often avoid. Trust us when we tell you it doesn't feel good to guess.

Legal documents and processes to think about when it comes to protecting your loved one's wishes can include advance healthcare directives, living wills and healthcare proxies, or Do Not Resuscitate (DNR). These documents are crucial in ensuring that you and your family can protect your loved one's wishes.

Consulting with legal professionals who specialize in elder law is essential to navigate these complex matters effectively.

Find legal, elder law, and estate planning resources at sandwichedkc.com/resources

FINDING HELP

What you need to know about finding help and hiring caregivers



Caring for a loved one is too big of a job for one person. It is important to look for people and resources to help.

DETERMINE YOUR NEEDS
It is difficult to ask for help if you aren't sure what type of help you need. Tools are available to help you determine what level of assistance your loved one requires and what tasks you can delegate to others.

Check out AARP's Prepare to Care guide as a starting point. The Guide includes a goals and needs checklist that covers each major area of life to help you make a plan.

It may turn out that you can find people to help or outsource several smaller tasks, ultimately freeing up bigger chunks of time for you to take a break or tend to your own needs.

ALL HANDS ON DECK
It is up to all of us collectively to care for our loved ones. Caregivers are often responsible for rallying the troops to get the help they and their loved ones need. The first place to find help is your personal network. Who do you know who cares about you and/or your loved one? Figuring out who is at your disposal may require you to spend some time mapping your loved one's relationships. Relatives, friends, and neighbors are normally happy to offer assistance, but they may need guidance on how they can lighten the load.

BRINGING IN OUTSIDE HELP
If you've figured out what kind of help you need, but don't have connections that can assist, you might have to hire outside help to provide home care.

RISKS OF PAYING PRIVATELY
If you decide that hiring private caregivers is the avenue you and your loved one want to take, you should know there are risks.

If you pay household employees over $2,700 a year, you are required to withhold taxes from their pay and report that income to the IRS.

When you hire private caregivers, you are responsible for thoroughly screening and properly training them. You may be required to purchase additional insurance coverage.

It may be a lot of work at first, but if you are able to manage the responsibilities of hiring your own caregivers, it may be well worth the reward.

Get help navigating home care at sandwichedkc.com



HOME HEALTH CARE VS. IN-HOME CARE

What's the difference?

If you're trying to sort out options for helping a loved one at home, the terms home health care and in-home care can get confusing. They sound similar, but they meet very different needs.

Home health care is medical help at home. Think of it as care prescribed by a doctor—like a nurse checking on medications, a physical therapist helping with recovery after surgery, or someone changing dressings and monitoring health. This kind of care is usually short term, covered by insurance, and tied to a specific health condition.

In-home care, on the other hand, is all about day-to-day support. Caregivers can lend a hand with meals, bathing, errands, light housework, or just keeping your loved one company. It's not medical, but it makes life at home safer and more manageable. Families usually pay for this privately, although some long-term care insurance may help.

The bottom line: home health care helps with medical needs, while in-home care helps with everyday living. Many families use a mix of both, creating a circle of support that keeps their loved one safe, comfortable, and right where they want to be... at home.

75% OF ADULTS AGED 50 AND OLDER WANT TO REMAIN IN THEIR CURRENT HOME AS THEY AGE.

-AARP'S 2024 HOME AND COMMUNITY PREFERENCES SURVEY



GETTING PAID TO CARE

Options for being reimbursed for the care you provide to a loved one



While some of us may be able to afford to provide this in-kind care to our family members, friends, and neighbors, others find that it comes at great sacrifice. Lost wages, abandoned jobs and careers, and financial issues are often faced by those who accept the call to help a loved one in need.

Caregivers often give a lot! Nobody should just be expected to perform all of the tasks that caregiving requires. **The simple fact is that if resources are available, family caregivers should be reimbursed for their time.**

Here are some common ways family caregivers get paid:

1. **Caregiver Contracts**
A caregiver contract is a formal agreement between a person who needs care (or their family) and the caregiver providing that care.

2. **Long-Term Care Insurance Policies**
Some LTC insurance policies include a provision for family caregivers to be paid. Contact the insurance company for guidance.

3. **Medicaid programs**
If your loved one receives or qualifies for Medicaid, it may be possible for you to be paid as their family caregiver through the Self-Directed Services or home and community-based services (HCBS) waivers.

4. **Consumer/Self-Directed Programs**
These programs, often offered through your Area Agency on Aging or a community organization that serves older adults or people with disabilities or complex medical needs, allow your loved one to pay you as their caregiver.

5. **Veteran's Benefits**
If your loved one is a veteran, they may qualify for the Veteran Directed Care Program and hire you as their caregiver. Contact your local VA to find out more.

Get help navigating caregiver assistance at sandwichedkc.com

MEDICARE & MEDICAID

Making sense of your loved one's benefits

MAKING SENSE OF YOUR LOVED ONE'S BENEFITS

"Getting Paid to Care" is about compensation for you. This is different: it's about understanding what Medicare and Medicaid actually cover for the person you're helping, because the gaps between what people assume is covered and what actually is cause real financial surprises.

MEDICARE, IN PLAIN TERMS

Medicare is health insurance, primarily for people 65 and older. It covers hospital stays, doctor visits, and some short-term skilled nursing or home health care, but it was never designed to cover long-term custodial care (help with bathing, dressing, meal prep) on an ongoing basis. This is the single most common point of confusion for family caregivers: Medicare will cover a short rehab stay after a hospitalization, but it will not pay for help at home indefinitely, and it will not pay for most long-term nursing home stays.

MEDICAID, IN PLAIN TERMS

Medicaid is different — it's a joint federal-state program based on financial need, and unlike Medicare, it can cover long-term care, including nursing home care and, in many states, home- and community-based services that help people stay out of a facility. Eligibility rules, covered services, and waiver programs vary significantly by state, so what's true for a loved one in one state may not be true in another.

WHERE CAREGIVERS GET TRIPPED UP

- Assuming a hospital discharge means "covered home care" will continue. It usually means a limited, time-boxed benefit.
- Not realizing Medicaid has strict asset and income limits, and that there are specific (and time-sensitive) rules around transferring or spending down assets to qualify.
- Missing state-specific waiver programs that can pay for in-home services for people who'd otherwise need facility care.

WHAT TO DO

- **Talk to a benefits counselor.** Many Area Agencies on Aging offer free Medicare counseling (SHIP programs) and can walk through your loved one's specific situation.
- **If facility care or long-term Medicaid may be in your future, talk to an elder law attorney before a crisis forces the timeline.**
- **Keep a running list of questions for your loved one's care coordinator or social worker.** Benefits questions are rarely a single conversation.

Understanding what's actually covered (and what isn't) is one of the most protective things you can do for your loved one's care and your own finances.





STATE HEALTH INSURANCE ASSISTANCE PROGRAMS

In Kansas?
Visit SHICK online at kdads.ks.gov

In Missouri?
Visit MO SHIP online at missouriship.org

State Health Insurance Assistance Programs, also known as SHIP programs, are certified by the federal and state government to provide free, unbiased, and confidential (private) Medicare services. SHIPs are not insurance companies. Many are housed within government or nonprofit agencies, and they do not sell anything or charge for their services.

SHIP programs have volunteer counselors and Community Partners who provide local Medicare counseling in their communities. These volunteers receive extensive training to become certified Medicare counselors and regularly receive updates and training.

AARP Kansas City

Raise your hand to support caregivers.

I AM A CAREGIVER

Join the fight at aarp.org/IAmACaregiver

/aarpmissouri @aarpmissouri

HOME-DELIVERED MEALS

Find local home-delivered meals, both nonprofits and companies, at sandwichedkc.com

Local meal delivery programs like Meals on Wheels bring meals to our family members, friends, and neighbors across the metro area each day.

Home-delivered meal programs are critical programs that not only ensure the health of the ones we care for, they interrupt the social isolation experienced by many of today's seniors who live on their own.

These programs, often powered by dedicated volunteers, deliver to our grandparents, moms and dads, neighbors, and friends, making it possible for many of them to live in their own homes and avoid placement in nursing facilities. They truly change lives.



Call 816-421-4980 to get started!

Are you caring for a loved one and don't know where to start? Do you wonder how to access home-delivered meals, transportation or legal services for your loved one?

Mid-America Regional Council (MARC) is your one-stop shop for caregiver connections in Jackson, Clay, Platte, Ray and Cass counties in Missouri.

Our services include:

- Information and referrals to increase your access to resources.
- Legal assistance with affordable end-of-life planning.
- GRAND*Pass* – A free week of summer camp for the children of older caregivers *(elegibility criteria applies)*.
- Home Safety Modification Resource Guide.

Caregiver Services at Mid-America Regional Council

TECHNOLOGY AS A CAREGIVING TOOL

Technology is transforming the caregiving landscape, offering innovative solutions to some of the most pressing challenges faced by caregivers. From health monitoring and medication management to smart home devices and emergency response systems, these tools enhance the quality of care, promote independence, and ensure the safety and well-being of our seniors.

Here are some key tech tools that are making caregiving just a little easier:

HEALTH-MONITORING DEVICES

Wearable health-monitoring devices like smartwatches and fitness trackers can monitor vital signs like heart rate, blood pressure, and oxygen levels. These devices often come with alert systems that notify caregivers if there are any irregularities, allowing for prompt medical attention. For seniors with chronic conditions, continuous monitoring can be a lifesaver.

MEDICATION MANAGEMENT APPS

Managing medications can be a challenge, especially when multiple prescriptions are involved. Medication management apps provide reminders for taking medications, tracking dosages, and even alerting caregivers if a dose is missed. Some advanced apps can integrate with pharmacy services to handle prescription refills.

TELEHEALTH SERVICES

Telehealth has revolutionized access to healthcare, making it easier for seniors to consult with healthcare providers from the comfort of their home. Video consultations can save time and reduce the need for transportation, which is particularly beneficial for those with mobility issues. Telehealth also allows caregivers to participate in appointments, ensuring they are informed and can assist in decision-making.

Find resources for technology and equipment at sandwichedkc.com/resources

SMART HOME TECHNOLOGY

Smart home devices, such as voice-activated assistants (e.g., Amazon Echo, Google Home) and smart thermostats, can significantly enhance the safety and comfort of seniors. These devices can control lighting, temperature, and security systems through simple voice commands, making daily tasks easier and promoting independence.

GPS TRACKING DEVICES

For seniors with dementia or Alzheimer's, wandering can be a serious risk. GPS tracking devices, often integrated into wearables, can help caregivers monitor the location of their loved ones in real time. These devices can send alerts if the person leaves a predefined safe zone, ensuring quick response in case of emergencies.

VIRTUAL COMPANIONS

Loneliness and social isolation are common issues among seniors. Virtual companions, powered by artificial intelligence, can provide interaction, reminders, and entertainment. These companions can engage in conversations, play games, and even remind seniors to take their medications or follow their daily routines.

EMERGENCY RESPONSE SYSTEMS

Emergency response systems, including wearable panic buttons and fall detection sensors, can immediately alert emergency services and caregivers in the event of a fall or other urgent situations. These systems provide peace of mind for both seniors and their caregivers, knowing that help is just a button press away.

As technology continues to advance, the possibilities for improving caregiving are boundless, offering new ways to support both caregivers and their loved ones.

CAREGIVING APPS

FOR MANAGING CAREGIVING CREWS AND CHECKING OFF LISTS

Caring Village
What it does: Offers shared daily notes, calendars, document storage, and task lists.
Why it helps: Everyone knows what's happening and who's responsible for what.

Lotsa Helping Hands
What it does: Creates a private care community to coordinate tasks.
Why it helps: Friends and family can sign up for meals, rides, or errands—no group text chaos required.

CaringBridge
What it does: Provides a secure place to share health updates and messages.
Why it helps: Keeps loved ones informed while saving you from repeating the same update dozens of times.

Meal Train
What it does: Simplifies organizing meal drop-offs from friends, neighbors, and family.
Why it helps: Takes one big daily stressor—"what's for dinner?"—off your plate.

Bottom line: These apps won't take away the challenges of helping a loved one, but they can help you feel more supported and less overwhelmed.



TECH TOOLS

FOR CAREGIVERS

Even though many of these tools and equipment are geared toward increasing the independence and safety of people in need of assistance, they often benefit those who provide that assistance by reducing caregiver burden.

MEALTIME

Make mealtime more manageable and comfortable with tools like **automatic feeders**, **adaptive utensils**, **non-slip placemats** and **plate lifters**, plate guards, and even hydration reminder bottles.

PERSONAL HYGIENE

Make bathing and personal care safer and more comfortable with tools like **shower chairs**, **grab bars**, **handheld shower heads**, **raised toilet seats and commodes**, **automatic soap dispensers**, and products like the **Blue Hug shower garment**.

MOBILITY

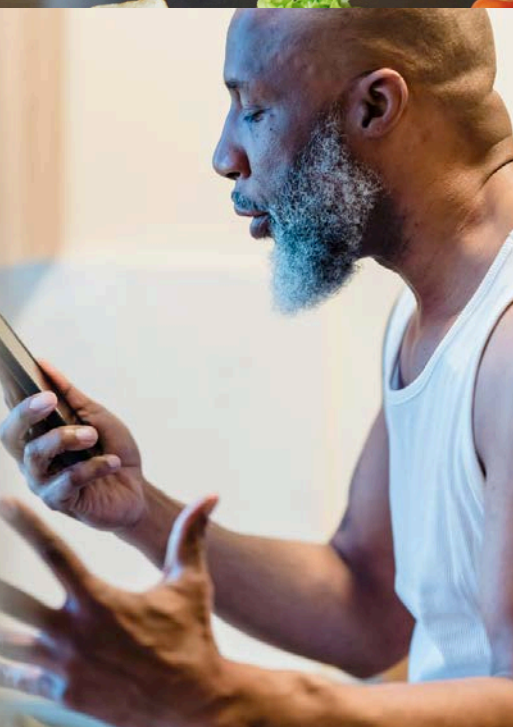
Enhance independence and reduce the risk of injury with **walkers** and **Rollators**, **lightweight wheelchairs**, **lift recliners**, **bed rails**, **car door handles**, and **swivel seats**.

SECURITY

Improve safety and provide peace of mind with tools like **fall detection devices and personal emergency response systems, smart appliances**, **video monitoring systems**, **GPS trackers**, **smart door locks**, and **medication dispensers with alerts**.







FAMILY DYNAMICS

WHEN SIBLINGS DISAGREE

Navigating family conflict over a parent's care

Few things test sibling relationships like a parent's declining health. Old patterns resurface — who was always "the responsible one," who lives closest, who has the closest relationship with Mom or Dad — and suddenly those patterns are deciding real things: medical choices, money, where someone will live.

WHERE THE FRICTION USUALLY COMES FROM

- **Uneven load.** One sibling handles daily logistics; others check in by phone. Resentment builds on both sides: the sibling doing the work feels unseen, the one farther away can feel shut out of decisions.
- **Different information.** The sibling present at appointments knows things the others don't, which can make decisions feel unilateral even when they aren't.
- **Old family roles.** Birth order, old rivalries, and long-standing dynamics don't disappear just because everyone is now an adult making medical decisions together.
- **Money.** Disagreements about paying for care, dividing an inheritance, or who gets reimbursed for time can turn practical disputes into something much more personal.

WHAT HELPS

- Hold a regular family meeting — even a recurring phone call — so decisions and updates happen in one place, not in a patchwork of one-on-one conversations.
- Divide tasks by strength, not just proximity. The sibling who's good with finances can manage bills remotely; the local sibling handles appointments; another handles research. Contribution doesn't have to mean physical presence.
- Consider a neutral third party for decisions that have stalled: a care manager, mediator, elder law attorney, or social worker can sometimes defuse what family alone can't.
- Separate the grief from the grievance. A lot of sibling conflict during caregiving is really grief wearing an argument's clothing... grief about losing the parent you knew, expressed as frustration with each other.

You don't need to resolve every old family pattern to care well for a parent together. You just need enough of a shared process that the care doesn't get lost in the conflict.

Connect with others who are dealing with sibling drama at our caregiver support groups.

“THE SANDWICH GENERATION”

Taking care of younger humans and older humans at the same time



If you’ve ever packed a school lunch and scheduled a parent’s cardiology appointment in the same ten minutes, you already know what it means to be “sandwiched.” You’re not choosing between your children and your parents. You’re trying to show up for both, often on the same afternoon, with the same tank of energy.

This generation of family caregivers is doing something relatively new in scale: living longer lives mean more years of overlap between raising kids and helping aging parents. The result is a kind of caregiving nobody trained you for… one where the needs rarely take turns.

WHAT MAKES THIS STAGE DIFFERENT

It’s not just busyness. It’s divided attention during the moments that matter: a child’s recital interrupted by a call from a parent’s doctor or a parent’s care plan meeting rescheduled around a kid’s fever.

Guilt tends to follow in both directions: guilt for the time you’re not giving your kids, guilt for the time you’re not giving your parent.

WHAT HELPS

- **Name it out loud.** Telling your kids (in age-appropriate terms) what’s going on with grandma or grandpa helps them understand why you’re stretched and can turn caregiving into a shared family value instead of a hidden stress.
- **Let one calendar hold it all.** Trying to keep caregiving logistics separate from family logistics usually backfires. One shared system reduces the mental load of constantly translating between two lives.
- **Borrow help where you can.** Carpools, meal trains, a trusted neighbor who can sit with a parent for an hour. Sandwich-generation caregivers often ask for help less because they’re used to being the one who gives it.
- **Watch for the quiet casualty: you.** This stage has a higher burnout rate than almost any other caregiving season, precisely because there’s no “off” role to step out of.

Being sandwiched means feeling pressed from both sides. You’re holding it all together, and you deserve support of your own. 🥪

Get help navigating sandwiched caregiving at sandwichedkc.com





CAREGIVING FOR A SPOUSE VS. A PARENT

Why the relationship changes everything

"Family caregiver" covers a lot of different experiences, and caregiving for a spouse is not the same as caregiving for a parent… even when the daily tasks look similar on paper.

CAREGIVING FOR A PARENT

There's often an existing hierarchy to renegotiate: you grew up being parented, and now you're making decisions for the person who once made them for you. Siblings are frequently part of the picture, for better or worse. And there's usually an "other life" to retreat to at the end of the day: your own home, your own household, some version of normal still running in parallel.

CAREGIVING FOR A SPOUSE

There's no stepping back into a separate life, because your spouse is your household, your routine, your partner in the very things caregiving now disrupts — finances, intimacy, future plans, daily companionship. The relationship you relied on for support is often the one that most needs supporting now, which can leave spousal caregivers with a particular kind of isolation: the person they'd normally talk to about a hard day is the hard day.

WHAT'S DIFFERENT, PRACTICALLY

- **Identity shift.** Spousal caregivers often describe losing the "partner" relationship before losing the person… grieving the marriage as it was, while the marriage continues.
- **Financial entanglement.** Shared accounts, shared income, shared retirement planning make caregiving decisions for a spouse inseparable from your own financial future in a way adult children don't usually face.
- **No built-in backup.** Adult children caring for a parent often share the load with siblings. Spouses frequently don't have another "first-line" person at all.
- **The future looks different, too.** Parent caregiving has a generally anticipated arc. Spousal caregiving can upend assumptions about your own retirement, aging, and later years in ways that are harder to plan around.

Whichever caregiving situation you may find yourself in, the tasks might overlap… but the grief, the identity questions, and the support you need often don't. It's worth seeking out people who understand your specific version of this role.

VETERAN & MILITARY CAREGIVING

Supporting those who served and those who serve them now



Helping a veteran, or a loved one still connected to military life, comes with its own landscape of benefits, culture, and challenges that general caregiving resources don't always address. Military family caregivers often take on this role quietly, without realizing how many programs and benefits exist for them.

This article covers what makes this role unique, which benefits exist, and where to turn first.

WHAT'S UNIQUE ABOUT THIS CAREGIVING ROLE

- **Service-related conditions.** Combat-related injuries, PTSD, traumatic brain injury, and exposure-related illnesses (such as those connected to Agent Orange or burn pits) can shape care needs differently than age-related decline alone.
- **A culture of self-reliance.** Many veterans are reluctant to ask for or accept help (a trait often reinforced by military culture) which can make it harder for family caregivers to get a loved one to accept services they're entitled to.
- **A complex benefits system.** Between the VA health system, VA disability compensation, and specific caregiver support programs, navigating what's available can feel like its own job.

BENEFITS WORTH KNOWING ABOUT

- **VA Program of Comprehensive Assistance for Family Caregivers (PCAFC):** provides a stipend, training, and support to eligible caregivers of veterans with qualifying service-connected injuries.
- **VA Aid & Attendance benefit:** an added monthly amount for veterans or surviving spouses who need help with daily activities, separate from standard VA pension or disability.
- **VA respite care and adult day health programs:** designed specifically to give military caregivers a break.
- **Vet Centers:** offer counseling for veterans and their families, often with less red tape than the broader VA health system.

WHERE TO START

Contact your nearest VA Caregiver Support Coordinator. Every VA medical center has one, and their role is specifically to help you navigate what you and your veteran qualify for.

Caring for someone who served comes with pride, and often with complexity most civilian caregiving guides don't touch. You deserve resources built for that specific experience.







SELF CARE & PRESERVATION

TAKING A BREAK

WHAT IS RESPITE?

Respite, simply defined, is taking a break from caregiving. Respite is not necessarily a service, program, or place.

PIECEMEALING IT

We wish we could tell you there was a one-size-fits-all solution to getting a break from caring for a loved one.

Often, helping a loved one age in place or caring for them in our homes requires creative solutions. These solutions normally come from a combination of sources: family members and friends and community resources.

There are limited programs and resources available that provide in-home and off-site respite. Some programs have strict eligibility guidelines. Some of them may be covered by private or public insurance or paid for out of pocket.

If your loved one can afford it or has long-term care insurance, you may consider hiring a caregiver to be with them while you take a break, whether it be privately or through an agency.

As with anything else in life, there are risks and rewards to both agency-based and private care.

OUT & ABOUT

If your loved one is able to get out of the house, one of the easiest strategies is to get them involved in the activities they can enjoy in the community. Finding a companion or hiring a caregiver may make this strategy a viable option if your loved one is unable to leave their home without assistance. Consider exploring activities and programming offered by the community centers, the library, senior center, faith communities, and local parks and recreation departments.

RESPITE RESOURCES

Your local **Area Agency on Aging** (AAA) may offer programs or funding to help you take a break. For the AAAs in the Kansas City area visit **sandwichedkc.com/resources**

Adult Day Care may be a respite option if your loved one needs constant supervision or assistance. Adult day services may be covered by private or public insurance or paid for out of pocket.

Faith communities may be a resource. Select parishes, temples, and ministries offer volunteer respite program to give those caring for family members a break.

Get help planning or finding respite at sandwichedkc.com



CAREGIVER BURNOUT & MENTAL HEALTH

When "tired" doesn't cut it

Taking a break helps. But some family caregivers reach a point where a few hours or a weekend off won't fix how they're feeling, and that's worth calling out: burnout, caregiver depression, and anxiety are distinct from normal exhaustion, and they don't resolve with rest alone.

SIGNS IT'S MORE THAN TIRED

- Persistent dread about caregiving tasks that used to feel manageable
- Irritability or numbness that doesn't lift after a good night's sleep
- Losing interest in things you used to enjoy
- Trouble concentrating, or a sense of being "checked out" even while physically present
- Intrusive worry or a racing mind that doesn't quiet down
- Physical symptoms with no clear cause: headaches, GI issues, chest tightness

None of these mean you're failing. They mean your nervous system has been running in a sustained stress state for a long time, and it's asking for more than a break can give it.

COMPASSION FATIGUE IS ITS OWN THING

Compassion fatigue shows up as emotional numbing, a sense that you have less to give, even to the person you love most.

It's common among people in caregiving roles for extended periods and is not a reflection of how much you care. It's a reflection of how long you've been giving without replenishing.

What to do next

- **Talk to your own doctor, not just your loved one's.** A primary care visit is a reasonable place to start naming what you're experiencing.
- **Look for caregiver-specific counseling or support groups.** Talking to people who understand the role can cut through isolation faster than general talk therapy sometimes can.
- **If you're having thoughts of harming yourself, or feel unable to keep going, that's urgent — not something to manage alone.** The 988 Suicide & Crisis Lifeline (call or text 988) is available any time.

Caring for yourself isn't separate from caring for your loved one. It's what makes caregiving sustainable. 🥪

SANDWICHED
family caregivers
of
KANSAS CITY

FIND **STRENGTH** IN COMMUNITY.

Join our family caregiver Facebook group.



Turning Point: We are here for you.

Suddenly, the course of your life changes unexpectedly. You or someone you love is diagnosed with a serious or chronic physical illness – and you need help coping with the new normal. ***Turn to us.***

Turning Point offers classes, resources and programs to support everyone affected – all with the goal of living life to the fullest. Because serious illness is a Turning Point. Most of our classes are held virtually.

TURNING POINT

THE UNIVERSITY OF KANSAS HEALTH SYSTEM

TurningPointKC.org
913-574-0900





BALANCING WORK & CAREGIVING

Caring for a loved one while working is a juggling act. It can feel like you're constantly on call… but with planning, support, and self-care, you can manage both roles without burning out.

1. KNOW YOUR WORKPLACE OPTIONS

Before making major changes, check what your employer offers. Ask about:

- **Family and medical leave**: FMLA or paid leave policies
- **Flexible schedules:** Adjusted hours, compressed workweeks, remote work
- **Employee Assistance Programs (EAPs):** Counseling, caregiving resources, referrals
- **Dependent care benefits:** Pre-tax accounts or stipends for caregiving costs

Tip: Even if benefits aren't advertised, HR may be able to help you find support.

2. EXPLORE FLEXIBLE WORK OPTIONS

If traditional schedules feel impossible, consider:

- **Freelancing or consulting:** Marketing, design, writing, tutoring, bookkeeping
- **Remote contract work:** Allows you to set your own hours
- **Part-time self-employment:** Offers control but may require handling your own benefits

Tip: Track your work hours carefully to avoid burnout and maintain income stability.

3. USE A CAREGIVING CONTRACT

A caregiving contract (or a personal care agreement) can:

- Define your responsibilities clearly
- Set compensation if family members are contributing financially
- Protect eligibility for Medicaid or other benefits

Tip: Work with an elder law attorney or financial planner to ensure the contract is legally sound.

4. BUILD YOUR SUPPORT TEAM

You can't (and shouldn't have to) do it all alone:

- **Family and friends:** Divide chores like transportation, meal prep, and appointments
- **Paid help:** Consider aides, cleaning services, or meal delivery
- **Community resources:** Adult day programs, respite care, local nonprofits

Tip: Regular check-ins with your team help everyone stay on the same page.

5. MAKE SELF-CARE NON-NEGOTIABLE

Caring for someone else can be exhausting. It's key to also make time for yourself:

- Schedule downtime like an appointment
- Prioritize sleep for energy and focus
- Seek support through friends, counseling, or caregiver groups

Tip: Even 15–20 minutes of "you time" daily can make a big difference.

"I CAN DO ANYTHING, BUT I CAN'T DO EVERYTHING!"

—Amy Goyer, AARP's Family Caregiving Expert

A FRAMEWORK FOR NAVIGATING DEMENTIA & ALZHEIMER'S

"There's hope in dementia. It lies in the way we provide care."
-JUDY CORNISH, CREATOR

the DAWN Method

The Dawn Method is an approach to dementia care that offers hope for individuals living with dementia and their caregivers. The basic tenet of the method, developed by Judy Cornish, is that while memory may fade, emotional intelligence remains intact.

The Dawn Method of dementia care empowers caregivers by shifting the focus from memory loss to emotional well-being, making caregiving a more positive and rewarding experience. By teaching caregivers to connect through emotions, create a supportive environment, and foster moments of independence, the method reduces stress and frustration.

The Dawn Method helps caregivers feel more confident and capable, enabling them to provide compassionate care while maintaining meaningful, joyful relationships with their loved ones.

At the heart of the Dawn Method is the belief that people with dementia can continue to live with dignity, happiness, and independence.

Instead of focusing on memory loss or cognitive decline, caregivers are encouraged to build a supportive, calm, and reassuring environment that fosters emotional security. This helps those with dementia feel safe, valued, and understood.

The approach focuses on five key principles:

1. **EMOTIONAL CONNECTION**
   Engaging with a person's emotions rather than their logic helps create a more comforting and meaningful interaction.
2. **EXPERIENTIAL WORLD**
   Since short-term memory is often impaired, the Dawn Method teaches caregivers to live in the present moment with the person, focusing on their immediate experiences
3. **SOCIAL SUCCESS**
   Helping individuals feel competent and confident through daily interactions maintains their sense of self-worth.
4. **AUTONOMY AND CHOICE**
   Providing opportunities for decision-making, no matter how small, fosters independence and a sense of control.
5. **MOOD MANAGEMENT**
   Maintaining a peaceful environment and supporting positive emotions helps reduce anxiety and frustration.

The Dawn Method offers caregivers a roadmap to creating a calm, loving environment, transforming the caregiving experience into one filled with connection and hope.

Find resources for Alzheimer's and dementia caregiving at sandwichedkc.com/resources

BOOKMARK, FOLLOW, AND SUBSCRIBE TO THESE

ONLINE EDUCATIONAL RESOURCES FOR DEMENTIA & ALZHEIMER'S CAREGIVERS



The Dawn Method
thedawnmethod.com



Teepa Snow's Positive Approach to Care
teepasnow.com



Be Light Care Consulting
belightcare.com



AlzAuthors
alzauthors.com



Dementia Darling
dementiadarling.com



Dementia CareBlazers
careblazers.com





PALLIATIVE AND HOSPICE CARE: WHAT YOU NEED TO KNOW

Clearing up common misconceptions about care for chronic conditions & end-of-life-care

Palliative care is a specialized form of medical care focused on providing relief from the symptoms, pain, and stress associated with serious illnesses. The goal is to improve the quality of life for both the patient and their family. Palliative care can be provided alongside curative treatments at any stage of the illness and involves a multidisciplinary team approach, including doctors, nurses, social workers, and other healthcare professionals who work together to address the physical, emotional, and spiritual needs of the patient.

Hospice care is a type of palliative care specifically designed for patients who are in the final stages of a terminal illness, typically with a life expectancy of six months or less. The focus is on comfort, dignity, and quality of life, rather than attempting to cure the illness. Hospice care provides comprehensive support to patients and their families, including pain management, emotional and spiritual support, and assistance with daily activities. Care is usually provided in the patient's home, but can also be offered in hospice centers, hospitals, or nursing homes.

DISPELLING HOSPICE MYTHS

1. **HOSPICE DOESN'T MEAN THAT YOUR LOVED ONE IS GOING TO DIE (soon... necessarily).** Let's face it. We're all going to die one day. Hospice services are typically called in when a person is expected to live six months or less.

2. **GETTING HOSPICE FOR YOUR LOVED ONE DOESN'T MEAN YOU WANT THEM TO DIE.** Getting hospice actually means that you believe your loved one deserves to be as comfortable as possible at the end of life.

3. **LOOKING INTO HOSPICE FOR YOUR LOVED ONE DOESN'T MEAN YOU'RE GIVING UP.** What it does mean is that you accept that you can do anything, but you can't do everything. Caregivers need a team, all the way up until the end.

Find palliative care and hospice providers at sandwichedkc.com/resources

COMING TO TERMS WITH END OF LIFE

BECOMING BETTER PREPARED

STEP 1: START THE CONVERSATION

***Caring Conversations®* materials** help families to prepare for serious illness or the end of life.

Also available: *Caring Conversations®* Workshop on YouTube gives an overview of end-of-life planning.

STEP 2: DO YOUR RESEARCH

Explore options for **alternative death care**, **funerals,** and **final arrangements**.

Consider aspects of end-of-life care beyond medical-emotional and spiritual.

Attend a **Death Cafe** to hear from others about their experiences.

STEP 3: GET IT IN WRITING

Sandwiched recommends consulting with an elder attorney to make sure all of the important legal documents are in place. Don't just arrange them for your loved one, get them done for yourself (You never know what could happen).

IT'S TOTALLY NORMAL

ANTICIPATORY GRIEF & AMBIGUOUS LOSS

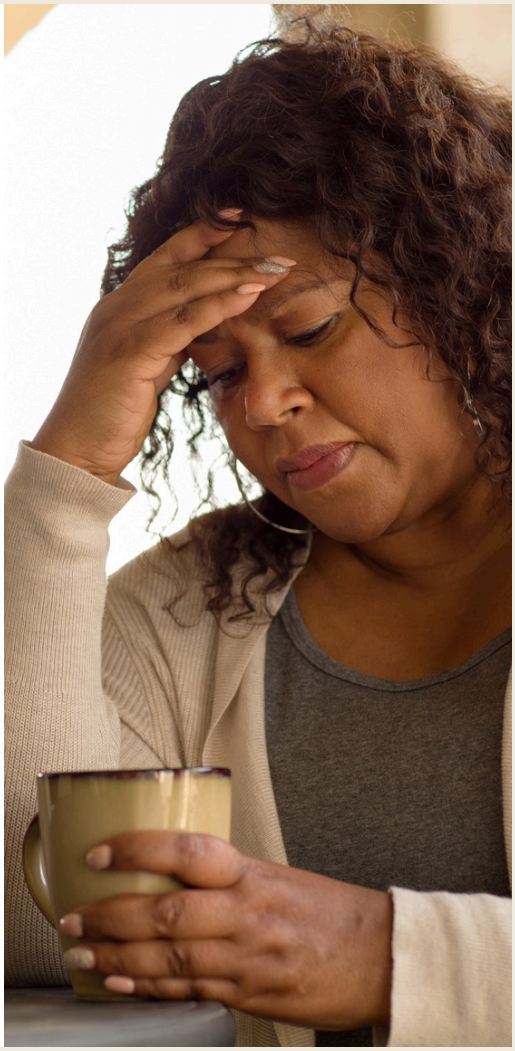
When someone you love is living with a serious illness, dementia, or another life-changing condition, you may grieve long before death. This is called **anticipatory grief**—mourning changes and future losses. You may also experience **ambiguous loss**, when your loved one is physically present but emotionally changed, or physically gone but still present in your heart.

These types of grief are uniquely difficult. There's no clear beginning or end, and often no rituals to help you process. You may swing between hope and sorrow, or feel guilty for grieving while your loved one is still here.

Ways to Cope:

- Embrace your feelings. Naming your grief can bring relief.
- Stay connected. Lean on trusted friends and family, or find a caregiver or grief support group.
- Create moments of meaning. Celebrate small joys and share stories.
- Practice self-care. Give yourself permission to rest.
- Seek guidance. Counselors or grief specialists can offer tools and reassurance.

Remember: Grief doesn't only follow loss. It can live alongside love, caregiving, and hope. Allowing yourself to feel and express it can make the journey lighter... for you and your loved one.





LIFE AFTER CAREGIVING

Helping a loved one is some of the most important work a person can do. When that role ends, whether because your loved one recovered, moved into long-term care, or died, life can feel strangely quiet.

Many family caregivers describe this season as relief and loss at the same time. Both can be true. You may find yourself asking: *What now?*

GETTING BACK TO EVERYDAY LIFE

Caregiving shapes nearly every part of your day: appointments, medications, household tasks, and a constant watchfulness over your loved one's safety and wellbeing. When that ends, the sudden open time can feel more disorienting than freeing.

Ease back in by:

- Reclaiming old routines at your own pace
- Returning to hobbies, exercise, or travel you set aside
- Reconnecting with friends and family who may have drifted

The goal isn't to return to your old life. It's to build a new rhythm that fits who you are now.

WHO ARE YOU NOW?

After months or years in the role, "caregiver" may have become your main identity. When the tasks stop, it's normal to feel unsure who you are without them. You might miss being needed, or feel guilty for enjoying a free afternoon. Give yourself time to rediscover what you like, what you want, and what you're good at beyond caregiving. Identity doesn't snap back on a schedule. It gets rebuilt through small, ordinary choices.

COPING WITH GRIEF

Even if your loved one is still alive, caregiving often brings feelings of grief. You may feel sadness, guilt, or a loss of purpose. These feelings are natural.

Some ways to cope include:

- Talking with a counselor, therapist, or support group
- Giving yourself permission to rest and heal without rushing
- Writing, drawing, or sharing your story as a way to process emotions

Grief is not something to "get over." It's something to carry with care, and it changes over time.

LIFE AFTER CAREGIVING
(continued)

COPING WITH GRIEF

Grief doesn't wait for a loss to arrive. Many family caregivers feel it during caregiving, too, as sadness, guilt, or a loss of purpose. These feelings are natural, whatever the situation.

Some ways to cope:

- Talk with a counselor or support group
- Allow yourself to rest without rushing
- Write, draw, or share your story as a way to process what you've been through

Grief isn't something to "get over." It's something you carry, and it changes shape over time.

PUTTING YOUR SKILLS TO WORK

Caregiving builds skills that carry into many parts of life, including:

- Hands-on care, such as personal care, transfers, and ostomy and catheter care
- Problem-solving under pressure
- Communicating clearly and advocating for others
- Staying organized and managing time
- Patience and compassion

Some former family caregivers turn these skills into new careers in healthcare, social services, or coaching.

Others pursue training or certifications to make their experience a professional path.

MAKING A DIFFERENCE FOR FELLOW FAMILY CAREGIVERS

Many people want their caregiving experience to leave something behind.

You might:

- Volunteer with groups that support family caregivers (we happen to know a good one)
- Share your story with someone just beginning their caregiving mission
- Speak up for better caregiver policies, services, and workplace support

These efforts honor your own journey and make the road easier for those who come after you.

Moving Forward

Life after caregiving is a time of change. It may take patience to find your footing, but it's also a chance to grow. By looking after yourself, using what you've learned, and sharing your story, you can move forward with strength and purpose.

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"THERE ARE ONLY FOUR KINDS OF PEOPLE IN THE WORLD: THOSE WHO HAVE BEEN CAREGIVERS, THOSE WHO ARE CURRENTLY CAREGIVERS, THOSE WHO WILL BE CAREGIVERS AND THOSE WHO WILL NEED CAREGIVERS."
—ROSALYN CARTER

SANDWICHED family caregivers of KANSAS CITY

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