Secrets No One Told You About FAMILY CAREGIVING

LEAN ON ME
Equipment That Helps

PUBLIC ENEMY No. 1
UTIs

BATHROOM BLUES

ADVICE FROM Nebraska Family Caregivers
Editor’s Note

Choosing to help your loved one with daily care is a deeply rewarding yet deeply difficult decision.

The delicate journey is paved with love, loaded with responsibility, and filled with daily concerns over how to do the best job while still caring for yourself.

We’ve put this guide together to offer some of the practical advice you may find you’ll need. You’re receiving this magazine because the agency that you’ve chosen to help your family is a member of the Nebraska Association of Healthcare & Hospice. Our members are strong believers in keeping families together, at home, where they most want to be. You’ve made a great choice!

Should you have any questions as you’re reading, or just need someone to talk to or listen, please don’t hesitate to call us at (402) 423-0718 or email us at nebraskahomecare@assocoffice.net. We are not a call center, but we would love to hear from you, and if we don’t have the answer we can point you in the right direction.

We wish you the best in your journey to help your loved one be safe and cared for at home. Please know that you are not alone. Thousands of Nebraskans are doing what you are, and many resources exist to help you!

Sincerely,

Janet Seelhoff
Executive Director
Nebraska Association For Home Healthcare and Hospice

As a person with aging parents, I understand the deep and delicate relationship shaped over a lifetime.

Telling a parent it’s time for help is never easy, but you’re not alone.

That is why we are dedicated to ensuring your loved one receives the compassionate care, consideration, and dignity they deserve.

“...and just as the sun sets and the moon appears, the stars shine to guide the way.”

—Unknown
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Find The Perfect Fit
Three Types of Home-Based Care

Today’s seniors and adults with disabilities may encounter three types of home-based care:

1. **Home Health**
   Medicare-funded home health is provided when a physician orders skilled care, including nursing, physical, occupational or speech therapy, or assistance by a home health aide, to individuals who are homebound and need medical care. This care usually lasts less than 60 days.

2. **Non-Medical Homecare**
   Non-medical homecare provides assistance with activities of daily living, such as bathing and dressing. This continuous care may be paid for by Medicaid if a person meets certain income and functional eligibility rules. However, most is paid for privately or through a long-term-care insurance policy.

3. **Hospice**
   Hospice, or end-of-life care, brings together medical care, pain management, and emotional and spiritual support for terminal patients and their families. This is covered by Medicare and Medicaid for people who have a life expectancy of six months or less.

All three types of providers are licensed by the Department of Health in Pennsylvania, and are surveyed regularly to ensure quality. The department maintains a complaint hotline, where consumers can report concerns or issues.

Nebraska Department of Health and Human Services Abuse and Neglect Hotline:
1-800-652-1999
Never believe that a few caring people can’t change the world. For, indeed, that’s all who ever have.

- Margaret Mead, anthropologist
Family members can be our greatest helpers – or our biggest obstacles!

Tension can build quickly if it feels as though the responsibility for care is being unfairly distributed among siblings. If you live closest, you might feel as if the caring role has been imposed upon you. One sibling may have always been meek; another may have always been argumentative. Long-held family roles can make this time difficult to navigate. Add a brother-in-law or sister-in-law to the mix and emotions can run high.

To avoid dissent, communicate early on about expectations and realistic contributions. It is true that other siblings’ commitments, geographic locations and financial situations can impact their ability to contribute the way you hoped they would. Everyone needs to put their wants and abilities on the table.

Where to Find Support

• The Family Caregiver Alliance offers valuable resources for connecting with support groups at caregiver.org

• AARP connects family caregivers online at aarp.org

• The Alzheimer’s Association offers support groups, research and other resources at alz.org or via its Helpline anytime of the day or night at 1-800-272-3900
Partner-In-Care:

3 Steps To Take Before Opening Your Home

Bringing a professional into your home, and trusting that person not only with your loved one but with your valuables, can feel a bit intrusive. Take these proactive steps to feel more comfortable with the caregiver in your home.

Do Your Homework
Ask the agency you’ve hired about its screening and training process. All caregivers must undergo a criminal background check. In addition, results of the agency’s surveys by the Department of Health are posted online at health.pa.gov.

Set Boundaries
While you’ll want to create a level of comfort and rapport with your professional caregiver, establish limits that will keep your privacy and household safety intact. For example, it’s OK to make areas of your home off limits to caregivers.

Protect Your Belongings
Instead of giving your caregiver a set of keys, purchase a lockbox. Place it outside your house with keys inside, allowing the caregiver to type in a code to retrieve them. You can easily change codes when you no longer want a caregiver to have access. Store valuables in a safe, and keep copies of important documents in a safe place. Also make note of all medications and any narcotics your loved one may be taking to ensure the pills are going only to them.

THE ART OF EMPATHY
Always share your loved one’s cultural and religious preferences with your professional caregivers. They might come from a different background than you and your loved one, and they may not know about certain aspects of the way you live.
HIRING A PRO TO GET MORE DONE

• Tell your homecare aide and agency what you expect. They can’t do what you want if they don’t know what you want
• If your loved one doesn’t like the caregiver after several visits, tell the agency. It’s OK! The important thing is for your loved one to feel comfortable
• If your caregiver is consistently late, talk about it. If the issue can’t be resolved, talk to the agency
• Have backup plans for care if your regular caregiver is sick. Your agency should have a plan, so know its protocol
• Regular meetings and open communication with your homecare aide and the agency can solve problems before they arise
• Ask questions! Professionals can give you tips on just about anything, from how to help your loved one get dressed to ways to avoid depression to a new food to try for dinner

While you may grow close to the homecare aides helping your loved one, always remember that it’s a business relationship.
You have to accept things the way they are but do what you can to make them better.
Facing difficulties from Parkinson’s disease and other health issues, Edward Dowd, a former insurance adjuster, moved into a nursing home. His wife of 51 years, Anita, realized it was not the right choice for them.

“He was unhappy in the nursing home, and I was unhappy always being there,” she said. “There’s nothing like being home.”

Tackling the challenges, the Dowds built an addition on their Carlisle home with hardwood floors and wide doorways so Edward could easily maneuver inside. They bought a specialized van to accommodate his wheelchair, and he moved back home.

“You have to accept things the way they are but do what you can to make them better,” Anita said. “Sometimes I lose my patience. It comes with the territory. But I just have a glass of wine and step back.”

The Dowds enjoy a few hours of homecare a day, which allows Anita to exercise, shop and care for herself.

“I’d be no good to him if I didn’t care for myself,” she said. “I rely on the homecare aides. We work as a team.”

Anita advises others in her shoes to explore all of the options and resources available.

“Get to know these resources and take advantage of them,” she said.
A BETTER BLUEPRINT

Preparing Your Home For Care
You’ve designed your home with comfort in mind, but put yourself in your loved one’s shoes – or walker or wheelchair. Is your home safe? Recognize hazards before they become detrimental to your loved one’s well-being.

Quick tips for making your house safe for your loved one:
• Avoid stairs. Create one-level living if possible
• Clear clutter. Keep floors free of obstacles
• Remove loose carpets
• Place non-slip mats under throw rugs
• Install good lighting
• Create accessible shelving to avoid bending and reaching
• Set up baby monitors
• Modify the house layout for wheelchair accessibility, if necessary
• Install ramps/lift chairs, if necessary

Banish Bathroom Hazards
The bathroom – close quarters, lots of porcelain and slick, wet surfaces – presents its own set of hazards for anyone with physical limitations. Minimize challenges in your loved one’s bathroom area:

- Install sturdy grab bars, weighted for a person, for the toilet and the tub/shower
- Simplify the shower/tub entry, if possible
- Add a shower chair or bench that enables a person who cannot walk to take a shower
- Install an easy-to-turn shower knob (note: hot water can scald skin)
- Install handheld showerheads
- Switch from soap bars to pump bottles
- Add extra lighting
- Install an accessible toilet: molded plastic seat, adjustable seat or new model
HAVING THE TALK

Life is filled with things we don’t want to talk about but know we should. It starts with the birds and the bees and continues all the way to how we want to spend our last days on Earth.

For all the soul-baring people do on social media and talk shows, you’d think we would be more comfortable discussing end-of-life issues with people who mean the most to us. But we’re not.

In fact, 90 percent of people say talking with loved ones about end-of-life care is important but only 27 percent have done so, according to a national survey conducted by the Conversation Project.

The Conversation Project is dedicated to helping people have “that” talk. It was co-founded by Pulitzer Prize-winning journalist and author Ellen Goodman after she was overwhelmed by the number and seriousness of the decisions she had to make when her mother’s health declined.

Avoid a Crisis

Don’t wait until there is a health care crisis to plan how to help your loved one. That’s the worst time to make financial and family decisions.

Talk with your loved one about what he or she envisions, and talk with your relatives about what help they can provide. Form a plan together that can be modified when it’s needed instead of starting from scratch during a health care crisis. An excellent place to start is Plan Your Lifespan at planyourlifespan.org. This is a website that will help you plan for health events from hospitalizations to memory loss and let you consider options long before you need them. Another resource is Five Wishes at agingwithdignity.org, an easy-to-use living will written in everyday language that can help start and structure important conversations about care.

Maybe the most important advice of all is to research your loved one’s financial situation so that you will know what services he or she can afford, if needed. A financially unrealistic plan is as bad as no plan at all.

- Do they have a will, advanced directive or POLST?
- Do they have long-term-care insurance? What does the policy cover? Is homecare included?
- Are they eligible for veterans benefits?
I realized only after her death how much easier it would have all been if I heard her voice in my ear as these decisions had to be made. If only we had talked about it.

– Ellen Goodman
It’s no secret that the cost of homecare can mount and mount quickly. Unfortunately, there’s not one program that provides payment for all the help your loved one needs. The best options often depend upon a quilt of services from businesses, social service agencies, nonprofits and insurers.
1. GOVERNMENT PROGRAMS
Medicare covers home health services like intermittent skilled nursing care, physical therapy, speech-language pathology services, occupational services and more. This care is brief, 60 days or less, and is ordered by a physician. Medicare also covers end-of-life hospice care if a patient has a life expectancy of less than six months.
If your loved one has very low income and few assets other than his or her home, Medicaid may pay for home-based care. In Pennsylvania, seniors can also receive financial assistance through the lottery-funded OPTIONS program.

2. VETERANS' ASSISTANCE
A program through the Veterans Administration assists chronically ill or disabled veterans of any age to remain in their homes as they age. For more information, visit va.gov and search for homecare.

3. PRIVATE INSURANCE
A long-term-care insurance policy may include coverage for homecare. Check with your carrier for details.

4. REVERSE MORTGAGE
Reverse mortgages were designed to help seniors stay in their homes until the end of their lives, enabling them to use the value of equity in their home to get cash now. Reverse mortgages apply only if your loved one is 62 or older and owns the home outright.

5. OTHER HELP
You could schedule a few hours each week at an adult day care program, a daytime program for older people in an interactive, supervised environment that costs less than homecare. The level of services varies from those that focus primarily on social interaction to those that provide medical care and those dedicated to Alzheimer’s care.
Lean on Me: Equipment that Helps

Homecare presents physical as well as emotional challenges when it comes to getting a loved one from one location to another around the house. Before you try helping your relative from bed to chair or chair to table, learn the safest way to avoid hurting them or yourself.

Durable medical equipment (DME) includes things like blood sugar monitors, walkers and wheelchairs. If insurance is to cover the cost, the equipment must be prescribed by a doctor for use in your home as medically necessary. Many of the items are covered by Medicare Part B.
To qualify for Medicare reimbursement, a DME vendor must be accredited by a professional entity such as The Joint Commission or the Community Health Accreditation Program. To find approved suppliers in your area, go to medicare.gov and under “Resource Locator” click on “Medical Equipment Suppliers.” Enter your ZIP code to find suppliers in your area. Your homecare or hospice agency also may be able to help you find a DME provider.

Gait belt
Wheelchair
Manual/Power Hoyer Lift
Slip Sheet
Hospital Bed
There are many devices on the market designed to increase safety and assist family caregivers. While you already might be using simple technology, such as a baby monitor, here is a sample of some other products created with elderly homecare consumers in mind.

I’ve Fallen, and I Can’t Get Up

Personal emergency response systems (PERS), sometimes called medical emergency response systems, give you and your loved one an extra layer of protection. They let you call for help in an emergency with the push of a button and sometimes even without a button.

You can buy, rent or lease a PERS, but they come with an installation fee and a monthly monitoring charge. These costs typically are not covered by insurance plans, although some hospitals and social service agencies subsidize the device for low-income users.

Other monitoring systems include video cameras in the home that can be accessed on a computer or your smartphone so you can monitor movement.

Telehealth

With the advent of telehealth services, it is becoming more common to be able to have virtual doctor visits or other health and safety monitoring services from a distance. Typically the services are provided via a computer link or over the phone, allowing your loved one to stay in place. Check with your doctor or your home health or homecare agency to see what telehealth services are offered and/or covered.

Medication Help

Worried that pills are not being taken at the right time or the right dose? There are remote medication dispensing and monitoring systems that can be programmed to dispense the correct dosage at the right time, as well as to notify caregivers if pills are not taken. Check with your homecare agency for more information.

Fall-Prevention Lighting

If you’re worried about your loved one falling at night, invest in lighting systems designed to automatically light up when someone steps on a pressure pad beside the bed. The lights will turn off when the person returns to bed.

Floor-Mat Alarm

For loved ones who have a tendency to wander, you can purchase a mat and place it by a doorway or next to the bed. It will sound an alarm if someone steps on it.

Home Motion Sensors

Several systems are designed to inform you about your loved one’s activity levels. These updates will give others a sense of what’s going on at home if you’re running errands and alert you if your loved one is unusually inactive and may need help.

Independent Living Aids

There are countless products and appliances that make everyday activities easier – from eating and preparing food to bathing and dressing.

- Kitchen items: easy-to-grip silverware, self-opening scissors, plate guards
- Bedroom items: bed bars, hip pads for fall protection, night lights
- Bathroom items: shower seats, toilet risers, long-handled scrub brushes
- Personal care products: no-rinse shampoo and body wash, buttonhooks, zipper pulls, pumps for soap and toothpaste

Research Before Purchase

Nebraska’s Assistive Technology Partnership through the State of Nebraska government is a resource guide to Nebraskans of all ages and disabilities.

For information and to view the catalog of resources available, visit atp.nebraska.gov or call 1-877-713-4002 (in-state only) or (402) 471-0734.
“Shawna had a different agenda,” Evelyn said. “She was a miracle baby.”

Shawna requires an extensive amount of care. Evelyn moved in with her parents so they could help with Shawna and her brother, Randy, who is three years older. Evelyn attended college, worked full time in retail and marketing, and cared for Shawna.

As Shawna became more medically fragile, Evelyn relied on nursing care to help. But being a full-time caregiver for her daughter opened a new world for Evelyn, who now also works as a caregiver at a home for people with autism.

“I found my passion in life through Shawna,” said Evelyn, who lives in Berwick. “She opened my world to a beautiful career in caregiving.”

Evelyn’s toughest challenge? Getting enough sleep. Three nights a week, nurses come to the home for eight hours so she can sleep for work. The other nights, Evelyn sleeps by her daughter’s side and is awakened every two hours by an alarm so she can check on Shawna.

“My biggest worry is that, if I don’t get enough sleep, I am going to miss one of her urgent alarms. It can be stressful,” she said, but added, “Shawna’s beautiful smile keeps me going.”

Evelyn even met her husband through one of Shawna’s nurses. In their 13 years together, they’ve been on only three dates because of the amount of care Shawna requires.

Evelyn said her husband respects and supports her, and she leans on him. And, while she believes God would not give her more than she could handle, she sometimes jokes that she would like just a little less.

Evelyn’s advice to other caregivers is never to give up hope.

“Research everything, and be an advocate for your loved one.”
Research everything, and be an advocate for your loved one.

— Evelyn Holmes, primary caregiver for her daughter, Shawna
6 Safety Tips for Prescription Medicines

1. Be alert for signs of side effects

2. Check medications for expiration dates

3. Don’t share prescription medicines

4. Keep medicine in a safe place, away from heat and small children

5. Keep a list of medications, dosages and reasons they were prescribed

6. Keep a list of when and how medicines are taken
DID YOU KNOW?

Side effects can impact thinking and balance. Often, you or your professional caregiver will be the first – and maybe the only – person to notice if your loved one doesn’t seem right. Some commonly used drugs are known to make thinking and balance worse in aging adults. These include:

- **Anticholinergics**, which include drugs for overactive bladder, itching/allergy, vertigo and nausea, and certain drugs for nerve pain or depression. Diphenhydramine, or Benadryl, is a commonly used anticholinergic.
- **Sedatives and tranquilizers**, often prescribed for sleep or anxiety. Examples include zolpidem and lorazepam, brand names Ambien and Ativan, respectively.

Contact your loved one’s doctor or other health care provider if something doesn’t seem right to you. You know your loved one the best.

MEDICATION MANAGEMENT

**Do you have a list?**
Always keep a current list of medications, including supplements and over-the-counter medications, as well as dosages. As medications change, update the list. Keep several copies in the house, with you and with your relatives.

**Did you tell your doctor?**
Make sure doctors are updated with your loved one’s medication usage, including over-the-counter medications and supplements. Never assume that doctors have a current list. Bring one with you to each appointment. You can even bring the bottles.

**Are these drugs OK together?** Make sure all of your loved one’s medications have been checked for potentially dangerous interactions. Include over-the-counter drugs and supplements. Ask your pharmacist or doctor. Your home health nurse can also review your prescriptions.

**Do you have medications that are expired or unneeded?** The safest bet for disposal: community-based drug “take-back” programs. Otherwise, almost all medicines can be thrown in the trash. Take extra care in disposing narcotics: Mix unused pills with an undesirable substance, like used coffee grounds, dirt or kitty litter. This makes the drug less appealing or unrecognizable to people. Your homecare or hospice agency can help you.
In caring for your loved one at home, you’re learning to manage challenges posed by mobility, memory, illness or a combination of those. Unfortunately, you’ve discovered — or soon will — there are some things no one wants to talk about. So we’ll say it for you…
Toileting issues are or will be a concern. Your loved one might be embarrassed to ask for help. You might be afraid to offer it. It's awkward. It's uncomfortable. Acknowledge that it's a sensitive topic for both of you, but it's an important part of daily life that you can help loved ones with, just as you might help them eat or get in and out of bed. For a host of reasons – health first and foremost – have the discussion as soon as any part of bathroom tasks becomes an issue. Ask which aspects of toileting your loved one finds difficult. Sitting down? Standing up? Reaching for supplies? Getting clean? Then work together to find acceptable solutions.

Just Can’t Go Can Get Serious

Not eating enough fiber or drinking enough water, being stuck in bed and taking certain medications can cause constipation, which can, unfortunately, result in bowel impaction. That means a mass of stool has blocked the colon and can't move. It can cause pain and vomiting, and result in hospitalization. Call the doctor immediately with signs of impaction.

To prevent constipation, especially if a person is taking a narcotic, Miralax or another stool softener will help keep things moving. Talk to your doctor or homecare agency for recommendations.

Under Pressure

Stay proactive in toileting techniques. Find a routine that works best for you and your loved one, and clean any bed leaks quickly because damp skin can lead to pressure sores.

Prolonged contact with water, urine, feces or sweat causes the skin to soften and break down. Change soiled clothing and bedding quickly, and ensure your loved one is clean and dry. If necessary, use a skin sealant or moisture barrier. Typically sold as creams or ointments with zinc oxide, lanolin or petroleum jelly, they form a protective barrier. Your doctor or homecare agency can recommend one.

Danger signs are areas of skin that are not broken but are red, discolored or show changes in hardness or temperature compared to surrounding areas. When you press on the area, it stays red and does not lighten or turn white and the redness is still there 30 minutes after the pressure is removed. Experts say a pressure sore at this stage can be reversed in about three days if all pressure is taken off of it. Call your doctor for assistance.

If the skin is broken, get pressure off of the site and call your doctor immediately.
A UTI, or urinary tract infection, happens when bacteria in the urethra, bladder or kidneys multiply in urine. Left untreated, a UTI can lead to acute or chronic kidney infections, which could cause permanent damage and lead to kidney failure. UTIs are a leading cause of sepsis, a potentially life-threatening blood infection.

Older people are more susceptible to UTIs for many reasons, from weakened immune systems and physical changes to weakened muscles and other medical conditions. While you can’t do much about physical bladder changes, you can keep your loved one clean and be alert for signs of a UTI.

A doctor can perform a simple urine test to detect a UTI, which can be treated with antibiotics. Your home health agency can perform this test at home with a physician’s order.

**Preventing UTIs**

- Good bathroom hygiene is essential to preventing infections
- Elderly people confined to bed need to be changed often
- Stay hydrated
- Hate water? Add flavored drink crystals, use bottled flavored water or try popsicles or Italian ice
- Use smaller drinking cups to make drinking seem less formidable
- Drink cranberry juice or take cranberry tablets to provide a less inviting climate for bacteria

**Think UTI Before You Think Alzheimer’s**

Typical signs of a UTI are a low-grade fever combined with pain during urination, frequent need to urinate and dark, bloody or foul-smelling urine.

According to the National Institutes of Health, a UTI in the elderly is often mistaken for early stages of dementia or Alzheimer’s disease because symptoms include:

- Confusion or delirium
- Agitation
- Behavioral changes
- Poor motor skills or dizziness
- Falling
Many Faces of Aging

We all notice an extra wrinkle or a gray hair here or there, but as we take care of aging loved ones, it’s sometimes surprising to see the many challenges they – and by extension you – might face. Some challenges we can lessen, and others we can at least be prepared for.
Skin Care

As we age, skin becomes thinner and drier, and it injures more easily and heals more slowly. All of that makes aging skin prone to problems from itching and flaking to serious infections and ulcerations. Be sure to check for sores or redness, potential signs of pressure sores – also called pressure ulcers or bedsores – which are injuries to skin and underlying tissue from prolonged pressure on the skin.

How to avoid pressure sores:
- Avoid hot baths and frequent showers
- Use mild soap
- Gently apply moisturizer to the skin after every shower or bath
- Always wear sunblock outdoors
- Stay hydrated
- Use a room humidifier in the winter and in dry climates
- MOVE! If your loved one is mobile, encourage walking. If not, reposition or transfer every 30 to 60 minutes

Stay Hydrated

Dehydration can lead to serious health problems. With age, the body’s ability to conserve water is reduced and the sense of thirst grows weaker. Sometimes chronic illness and certain medications dull the desire to drink water, but the need remains.

- Drink small amounts of fluids throughout the day instead of large amounts all at once
- Foods high in water such as fresh fruits and vegetables help meet daily needs
- Have water, juice or milk with every meal, and keep favorite drinks nearby

Warning signs of dehydration
- Fatigue
- Dizziness
- Dark urine
- Headaches
- Dry mouth/nose
- Dry skin
- Cramping
Bare Your Sole
Feet Can Give Clues To Health

Experts say the best way to check someone’s health is to look at their feet. Your feet allow you to stay active and keep your balance, and they can be a sentinel of health concerns such as diabetes, arthritis, poor circulation and nerve damage. Remind or help your loved one to check his or her feet every day, and be on the lookout for ingrown toenails, corns and calluses. Feet should be kept clean and dry. Use comfortable socks, and change them regularly. Ensure shoes fit well and are supportive. If anything looks out of the ordinary, talk to your doctor.

It’s not a bad idea to have your loved one see a podiatrist, a physician who specializes in foot and ankle care. Podiatrists can do everything from clipping toenails to performing foot surgery, and many do home visits. Ask your doctor or other health care provider for more information.
**Osteoporosis**

Osteoporosis, or low bone mass, can put your loved one at risk of a fracture.

- Ensure an adequate intake of calcium and vitamin D with a healthy diet of dairy products, green vegetables, fatty fish like salmon and tuna, and drinks fortified with calcium and vitamin D. Ask your doctor about supplements.
- Get as much weight-bearing exercise such as walking and weightlifting as possible.
- Limit alcohol use.
- Consult your doctor about medication to build bone strength.

**Shingles**

If your loved one had chickenpox as a kid, the virus can re-emerge as shingles in adulthood. One of three people over 60 will get shingles, and 50 percent of all Americans will experience it before they're 80. It starts with severe pain or tingling and develops into an itchy rash and possibly blisters. There's a vaccine available, so talk to the doctor. See if you can get the vaccine, too.

**Memory Loss/Pulling Away**

Many people think that memory loss is inevitable with aging and nothing can be done about it. That's not necessarily the case. Aging brains can have difficulties with recent memories and multitasking, and it can just take longer to recall information. Other factors like medication or hearing loss can add to the problem. Reducing stress, eating healthy and staying mentally stimulated can help.

Oftentimes, older people can disengage from the world around them, withdrawing from family, friends or activities they once loved to do. This can be caused by a variety of different factors, and you as the family caregiver should do all you can to keep your loved one connected and engaged. Some great activities including playing BINGO or card games, and looking at old photos of family and friends and keeping those memories fresh.

Other brain-boosting strategies:
- Exercise your brain — Do crossword and word puzzles, learn a new language, play card games
- Socialize — Getting out and about wards off depression and anxiety, which both contribute to memory loss

**Obesity**

As the numbers on the scale increase, so does the risk of chronic problems such as heart disease, diabetes and cancer. Often, people just aren't as active or mobile as they once were. Caregiving can be more challenging if the person is overweight, especially for transferring. You and your loved one should talk with your doctor about the safest ways to stay active, eat right and avoid extra weight, but always discuss it with love and respect.

**Gum Disease**

Healthy teeth and gums are important for smiling, eating and overall health. With age, a person's mouth tends to become drier and cavities are more difficult to prevent. Some medications dry the mouth and foster bacteria overgrowth. Studies suggest that oral bacteria and gum disease play a role in diseases such as diabetes. Regular dental checkups and good oral health should be a priority. If your loved one has dentures, make sure they are cleaned daily and soaked overnight.

**Flu and Pneumonia**

The smart choice is to get vaccinated against both. Anyone over 65 is at risk of complications from the flu. Pneumococcal pneumonia is a potentially fatal flu-related complication. You can get the pneumococcal vaccine your doctor recommends when you get the flu vaccine. Medicare typically pays for these vaccines.

**Diabetes**

Diabetes can be identified and addressed early with simple tests for blood sugar levels. The sooner you know if your loved one has it or is at risk, the sooner diet and lifestyle changes can be implemented to improve long-term health.
Retired middle school teacher Ida Flanders has been husband William's primary caregiver, with help from a homecare agency, since his fourth stroke in 2012 left him unable to walk and with cognitive and memory issues.

After being married to William, a retired carpenter, since 1963 and raising two children, Ida wasn't interested in moving him to a nursing home or other facility.

“They don’t have the time to do what I do,” she explained. “They have many people to care for. I just have one.” Her biggest challenge, however, and one of her most important tasks is to take care of herself.

“I am always so focused on getting him his meds and making sure he eats, sometimes I forget my own medicine,” she said, laughing. “If I’m not well, I can’t care for him.”

When the homecare aides come to their Philadelphia home, Ida goes to the grocery store, hits the gym or otherwise finds time for herself.

Another outlet for Ida, who is training to operate her own online travel company, is work-related travel. When William is able, he joins Ida with the help of an aide.

“We do a lot together, but we have separate time as well,” she said, and she sees how easily she could burn out without the time away.

In fact, she uses a travel analogy to describe being a family caregiver. Flight attendants tell passengers that in case of emergency to put on their own oxygen mask before helping someone else with theirs. It’s advice she follows so that she and William can both stay healthy.
If I’m not well, I can’t care for him.

“Family caregivers experience burnout when they are not getting enough sleep, taking time for themselves, exercising or eating properly,” she said. “I take care with gladness and joy when I have that break. It’s not being selfish. It’s being thoughtful.”
Find Your Zen

While modern medicine has progressed by leaps and bounds in letting us control chronic conditions, live healthier lives and overcome pain, it can’t solve all problems. Don’t be afraid to explore non-prescription options for everything from pain control to improved mental health. Always talk with your loved one’s doctor about alternative measures you are considering. Your homecare or hospice agency can point you in the right direction.
Dementia is a general term for a decline in mental ability severe enough to interfere with daily life. Memory loss is an example. Alzheimer’s is the most common type of dementia and causes problems with memory, thinking and behavior. Symptoms usually develop slowly and get worse over time, becoming severe enough to interfere with daily tasks.

Alzheimer's is not a normal part of aging and worsens over time. The disease typically progresses slowly in three general stages – mild (early stage), moderate (middle stage) and severe (late stage). Because Alzheimer’s affects people in different ways, each person will experience symptoms differently.

A diagnosis of early-stage Alzheimer’s disease doesn’t just affect those with the disease; it affects everyone who loves and cares about them. As a care partner (a term many choose to use rather than “caregiver,” because a person in the early stage of dementia may not need much assistance), you may find yourself in a new and unfamiliar role. You may be unsure of where to go for information, anxious about what to expect as the disease progresses and concerned about your ability to support the person living with dementia.

Take advantage of available treatments, participation in clinical trials and involvement with support groups and other resources. Taking advantage of all these benefits can reduce anxiety about the unknown and lead to better outcomes for everyone involved.

While there is no cure, treatments for symptoms are available and research continues.

Visit alz.org for more information.
Help Yourself: 9 Ways to Avoid Caregiver Burnout

Experts say building time into your routine to take care of yourself can keep depression at bay. To effectively care for others, you first have to care for yourself. Set aside all the “shoulds” and put yourself at the top of the list.

1 Take a break.
Read a book, attend a religious service, watch a movie or call a friend. Taking a breather gives you a fresh perspective.

2 Ask for help.
And accept help when it’s offered.

3 Reach out.
Spending time with friends and other family members helps you recharge and decreases feelings of isolation.

4 Exercise.
Go for a walk, do yoga or ride a bike. Research shows regular physical activity can help prevent depression and alleviate anxiety.
5 Be healthy.
Take care of your health. Eat well, get plenty of sleep and see your doctor when needed.

6 Have a laugh.
Laughter is great for stress relief, so watch a funny movie, catch a comedy clip on YouTube or share a joke with a friend.

7 Catch a tune.
Match your mood: calming music to subdue frustration, energizing tunes to get your adrenaline pumping or a classic favorite to make you smile.

8 Group support.
Find a local support group through your homecare or hospice agency, or join an online support group. Vent to a friend. Let it out and leave it there.

9 Forgive yourself.
It’s normal to feel tired, frustrated or even angry at your circumstances or with family members who are not doing as much as they could.

DID YOU KNOW?
Back injuries are the No. 1 caregiver injury. Be safe! Caregivers should follow basic safety techniques:
• Align your head and neck with your spine
• Avoid bending at the waist
• Don’t twist your body when carrying
• Keep your body close to theirs
• Spread your feet shoulder-width apart to maintain balance
• Keep knees slightly bent and hold in stomach muscles
• Use your leg muscles for lifting and pulling
Clean as you go! When caring for a loved one at home, there is no, "I will get to it later." Clean as you go to maintain organization.

Carry a small notepad and pen throughout the day. As caregivers, we are already working overtime, which means our memory is doing double time. Don’t try to remember "was it soap and bananas we need at the store?" or "did the doctor just call and say he wanted to see Mom Thursday or Friday?" or "was it 2:00 or 3:00 that Dad took his meds?" Write it down … a notepad is like a mini survival kit!

Invest $1 in a plastic clip that looks like a clamp and is often used to seal a chip or cookie bag. This plastic clip is a workhorse: in the bathroom to clip a towel around your mom when she is chilly to allow both of your hands to be free to safely transfer; at the dining table to clip and drape a dishtowel around Dad’s neck, or when assisting with toileting to clip a dress or nightgown up to keep it from getting soiled.

— Anne Pannone
BAYADA Home Health Care

Anne Pannone knows a thing or two about caregiving!

“Being creative in homecare is like coloring outside the lines in a coloring book – something wonderfully unexpected might happen!”

Named the 2017 Pennsylvania Direct Care Worker of the Year by the Pennsylvania Homecare Association and the Department of Aging, Anne is dedicated to keeping people safe at home. She understands the importance of person-centered care and takes great measures to ensure that the consumers she serves are treated with the utmost dignity and respect. In fact, she once walked almost 10 miles during a weekend snowstorm to make sure the people she cared for had what they needed and weren’t alone.

So what is Anne’s advice to family caregivers like you?

1. Clean as you go! When caring for a loved one at home, there is no, "I will get to it later." Clean as you go to maintain organization.

2. Carry a small notepad and pen throughout the day. As caregivers, we are already working overtime, which means our memory is doing double time. Don’t try to remember "was it soap and bananas we need at the store?" or "did the doctor just call and say he wanted to see Mom Thursday or Friday?" or "was it 2:00 or 3:00 that Dad took his meds?" Write it down … a notepad is like a mini survival kit!

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Don’t try to be a superhero!

Don’t do it all yourself, and don’t give up everything else you do. Set up a plan, make sure it works and pay attention to see when it needs to be changed.

Being a family caregiver isn’t easy but is rewarding. Always feel good about the choices you’ve made to help your loved one. Your hard work is appreciated.

Remember, you’re not alone. NAHHH is just a call or email away at (402) 476-0718 or nebraskahomecare@assocoffice.net.

Find additional resources at our website, nebraskahomecare.org.

Christopher Reeve

I think a HERO is an ordinary individual who finds strength to persevere and endure in spite of overwhelming obstacles.
Secrets No One Told You About Family Caregiving is a publication of the Nebraska Association For Home Healthcare and Hospice. We are so thankful for the support of our dedicated community of member organizations. Thank you for allowing us to be a guest in your home.