

TAKE CARE

A Guide for Family Caregivers



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DEAR READER,

Perhaps you're wondering, *Am I a caregiver?* According to Jeremy Barron, M.D., medical director of the Beacham Center for Geriatric Medicine at Johns Hopkins, "It's often difficult to say exactly when caregiving starts because caregiver identities and responsibilities vary greatly." You may have a family member (often a spouse) living with you under your full-time care. Or you may be supporting a loved one facing health challenges but living independently, even across miles. You may be taking a friend to doctor appointments and picking up medications. All of these situations make you a caregiver.

As one of the four in 10 adults in the United States who are caregivers, you're in good company. You've taken on a role that offers rewards for both you and your loved one.

“Caregiving brings huge improvements in the quality of life and health care of a loved one.”

There are actually positive chemical changes that occur in the brain when we do something meaningful for someone else.”

But that doesn't mean being a caregiver doesn't bring stress. That's where this resource comes in. Whether or not you've reached the point at which you're feeling stressed—even a bit—it's crucial for caregivers to seek assistance. Here at Johns Hopkins Medicine, we know that no one can or should have to do it alone. We work together as a team, and now we are part of *your* support team too. This guide is the first step in helping you become well-informed and find the support you need. By doing so, you'll be better able to care for your loved one while maintaining your loving relationship and your own good health.


**MEET
OUR
EXPERTS**
JEREMY BARRON, M.D.

Medical director of the Beacham Center for Geriatric Medicine at Johns Hopkins Medicine

ALICIA ARBAJE, M.D., M.P.H.

Johns Hopkins geriatric medicine physician

PARTNERING WITH HEALTH CARE PROVIDERS

For the best care, use this expert-approved doctor discussion guide for caregivers.

THERE IS A DEMONSTRATED link between good doctor-patient communication and better health outcomes, including improved treatment results, reduced patient stress and better medication compliance. As a caregiver, you are a participant in these health care conversations, which can be very helpful to the patient. Well-known research has shown that when patients leave a doctor's office, they forget as much as 80 percent of what the doctor told them. "Older patients who are accompanied by a caregiver remember more from their appointments, and they experience an improved satisfaction with their medical care," comments Johns Hopkins expert Jeremy Barron, M.D.

PARTNER FOR CARE

Talk with your loved one about needs, goals, wishes and fears about the future. "Get clear on what's most important to the person being cared for," says Alicia Arbaje, M.D., M.P.H., a Johns Hopkins geriatric medicine physician. "We call them *goals of care*." Maybe your loved one would like to eat dinner with family, attend worship services and participate in a favorite hobby. Knowing those goals can help both you and the health care providers make informed recommendations.

TALK WITH THE TEAM

At any appointment, you, the patient and the health care provider may all have different goals. So it's important to prepare.

Do a health review.

Ask your loved one to share top concerns, including physical and emotional symptoms, social or environmental worries (such as a death in the family or a recent move), and functional concerns (such as mobility, driving and continence). Find out when, if at all, your loved one would prefer you exit the exam room.

Plan like a business meeting.

"Create an agenda and a goal for the appointment," says Arbaje. "Be prepared with three questions or topics to discuss." If you have more than three concerns, address the most critical first. If possible, email the agenda to the health care provider in advance. Then write down or record (with permission) what you're told so you don't duplicate questions or forget information.

Follow up as needed.

Schedule another visit to discuss uncovered issues, or ask if you can email or call about them.



ASK THE EXPERT

WHEN SHOULD MY LOVED ONE SEE A GERIATRICIAN?

Anyone age 65 or older can benefit from seeing a geriatrician, but the American Geriatrics Society recommends that a senior with three or more conditions seek a geriatrician's care. (That's roughly 50 percent of all seniors.) Geriatricians are primary care doctors who specialize in treating conditions common among older adults. These professionals can also help caregivers manage and coordinate care for multiple conditions, and they can connect caregivers with a network of resources, including social workers, nutritionists, specialists and transportation services. Some geriatricians function as health care consultants rather than health care providers. They may also refer you to geriatric specialists, such as geriatric oncologists and geriatric cardiologists.

—JOHNS HOPKINS EXPERT JEREMY BARRON, M.D.

GETTING THE CONVERSATION STARTED

To help build a list of questions for the health care team, use these guidelines.

WHAT TO SHARE

- Introduce yourself and what your current role is as a caregiver.
- Supply your contact information.
- Explain the patient's *goals of care* (see page 2).

- Share a list of the patient's current medications and treatments (see page 6).

WHAT TO ASK

What is the patient's current diagnosis and health status?

Will this patient need any medical tests or procedures before the next appointment? Which ones, why and when?

What symptoms or changes in medical condition should we watch for? If they occur, what should be done and who should be called?

What can I do as a caregiver to improve the outcomes for this patient?

When is a follow-up appointment needed and with whom?

Does this patient need any referrals from you at this time?

80%
How much information patients have been shown to forget when they leave their doctor's office.

CARING FOR YOU

You can use these same tips when attending your own medical appointments. Print two copies of this worksheet, and fill out one with your medical information and questions, then use the other for your loved one.

QUICK REFERENCE

HEALTH CARE PROVIDERS

PATIENT'S NAME: _____

PRACTICE/ PROVIDER NAME	ROLE/CONDITIONS TREATED	CONTACTS (PHONE/EMAIL)	NOTES
1. _____ _____ _____	_____ _____ _____	_____ _____ _____	_____ _____ _____
2. _____ _____ _____	_____ _____ _____	_____ _____ _____	_____ _____ _____
3. _____ _____ _____	_____ _____ _____	_____ _____ _____	_____ _____ _____
4. _____ _____ _____	_____ _____ _____	_____ _____ _____	_____ _____ _____
5. _____ _____ _____	_____ _____ _____	_____ _____ _____	_____ _____ _____
6. _____ _____ _____	_____ _____ _____	_____ _____ _____	_____ _____ _____
7. _____ _____ _____	_____ _____ _____	_____ _____ _____	_____ _____ _____
8. _____ _____ _____	_____ _____ _____	_____ _____ _____	_____ _____ _____

WHAT TO KNOW ABOUT MEDICATIONS

Overwhelmed by pill bottles and prescription side effects? Get organized, starting now.

“MEDICATIONS ARE THE SINGLE MOST challenging aspect of health care, because they’re taken daily and there are so many complications that can occur,” says Alicia Arbaje, M.D., M.P.H., a Johns Hopkins geriatric medicine physician. A little expert guidance can make navigating medications easier for you and your loved one.

BEGIN WITH A PRESCRIPTION REVIEW

One of the first things you should do as a caregiver is gain an understanding of the medications that your loved one is taking. “In medical school, we doctors learn how to prescribe medications, but we don’t talk much about how to unprescribe them,” says Arbaje. It’s possible that your loved one is taking more medications (or higher dosages) than needed. Make sure to schedule a few annual medication reviews with your loved one’s primary health care provider. At the appointments, ask these questions about each medication.

- 1. Does my loved one still need this medication?** Does he or she still have the condition that it was prescribed to treat? Is the medication treating it effectively?
- 2. Does the dosage need to be adjusted for any reason** (such as a change in weight or symptoms)?
- 3. What lifestyle changes could help** my loved one no longer need this medication?



NEW SYMPTOM? CONSIDER THIS

“When I see a new symptom in an older person, I look at whether it might be a medication side effect,” says Arbaje. Sometimes older adults are prescribed a medication and then develop a side effect, which the doctor treats by prescribing another medication. A better approach, says Arbaje, is to switch the original medication.

DON’T FORGET ABOUT FOOD

“The most important ‘medication’ is food,” says Arbaje. Your loved one will feel better overall when nourished and hydrated. Many medications also work better with the proper diet. Concerned about your loved one’s eating? Have a separate nutrition-related discussion with a doctor or nutritionist.

ASK THE EXPERT

HOW CAN I ENCOURAGE COMPLIANCE?

If your loved one is not taking his medication as prescribed, ask him questions to uncover barriers. Can’t swallow pills? The pharmacist may be able to supply a liquid form. Side effects problematic? Talk to the prescribing physician. Make sure all of the medications are still necessary; the fewer the patient takes, the easier it is to comply. If the patient doesn’t know why the medications are important, use a permanent marker to write that information on the package (example: blood pressure, diabetes, pain). Also draw a big star on the medications that matter most to achieving the patient’s goals of care. Last, ask how you can help organize the doses. Pharmacists can package each day’s pills separately, you can place medications in an organizing dispenser, or you can create a daily checklist or spreadsheet.

—JOHNS HOPKINS EXPERT
ALICIA ARBAJE, M.D., M.P.H.

SINGLE PHARMACY: A SMART APPROACH

Fill all of your loved one’s prescriptions at the same pharmacy. This way, the pharmacist can track any drug interactions, side effects and problems taking a particular medication. You can also consult with the pharmacist regarding the patient’s health concerns and any drugstore items that may be of assistance.

QUICK REFERENCE

MEDICATION OVERVIEW

Include prescription medications; over-the-counter medications taken regularly; and herbs, vitamins and other supplements.

PATIENT'S NAME: _____ **BIRTH DATE:** _____

DATE CHARTED: _____ **MEDICATION ALLERGIES:** _____

NAME OF MEDICATION: _____

What it treats: _____

What it looks like: _____

Prescribing physician: _____

Date first prescribed (if known): _____

Dosage, frequency and time of day taken: _____

Special instructions: _____

NAME OF MEDICATION: _____

What it treats: _____

What it looks like: _____

Prescribing physician: _____

Date first prescribed (if known): _____

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ORGANIZING MEDICAL RECORDS

These tips help you tame the paper tiger and improve your loved one's level of care.

ORGANIZING YOUR LOVED one's medical records can help you better understand the big picture regarding that person's health. "Also, in an emergency, it's important for health care providers to know the patient's current health status and the results of recent tests. Having this key information quickly at hand helps patients better interpret what they're seeing and decide upon the best course of action," says Alicia Arbaje, M.D., M.P.H., a Johns Hopkins geriatric medicine physician.

CONSIDER ORGANIZING ONLINE While paper files work fine, online tools can help you gather, store, review and share health care documents and information. Electronic records can be easily accessed from any computer or smartphone,

CARING FOR YOU

If you create an online account for managing your loved one's health records, do the same for your own. This can make your life easier when it comes time for *your* next medical appointment.

and won't be damaged or destroyed by a flood or fire. Also ask labs, pharmacies and other health care providers if they offer apps or websites that allow you to access test results and other health information. If your loved one already has some health information stored online, discuss how you can gain access, if needed. For example, are there log-ins and passwords you should know and store in a secure place?

DISCUSS ADVANCE DIRECTIVES

These legal documents allow patients to identify who should make decisions on their behalf if they are not able to, as well as their wishes regarding treatments such as life support measures. The *living will* typically addresses the type of care desired, and the *medical power of attorney* (also known as a *health care proxy* or *durable power of attorney*) names the people who will be responsible for this care. For more information, call your loved one's geriatrician or hospital, or visit the website for the National Hospice and Palliative Care Organization at caringinfo.org.



INFORMATION WORTH SAVING

RECORDS MORE THAN A YEAR OLD CAN BE PACKED AWAY. KEEP DOCUMENTS SUCH AS THESE FROM THE PAST YEAR READILY ACCESSIBLE.

- A family health history
- A personal health history (current conditions and treatments, plus important past surgeries, accidents and hospitalizations)
- Doctor visit summaries and notes
- Hospital discharges
- Pharmacy printouts for prescribed medications
- Test results (such as blood work, urine tests, X-rays, MRIs, bone density scans, mammograms and prostate screenings)
- Bills and insurance forms related to medical treatment

MANAGING FINANCES

Understand your loved one's financial picture to help make the most of it.

FINANCES ARE TRICKY TO NAVIGATE—SO MUCH depends on the caregiving relationship and your loved one's condition. In general, the sooner you discuss finances, the better. (Spouses caring for spouses may be a step ahead.) If possible, broach the topic *before* problems arise so your loved one can walk you through investments, accounts, insurance and other financial information. "Ask your loved one who they would like to handle their finances if they are no longer able to," says Alicia Arbaje, M.D., M.P.H., a Johns Hopkins geriatric medicine physician. "That person may not be the same one who manages health care or household tasks."

GETTING ASSISTANCE

Although not all of these suggestions may be relevant to every situation, here are some smart steps to getting financial information and support.

Visit your loved one's financial institutions. Find out if they offer discounts or services for older adults. Also meet with an adviser to learn how to assume responsibility for accounts and to reassess investment strategies.

Bank online. Look into automatic or online bill paying and direct deposit of checks, such as Social Security and pension income. Find out if there are any associated fees.

Consolidate credit cards. Consider paying off and closing those with the highest rates and fees or the fewest perks.

Seek a specialist. If the finances are complicated or in disarray, look for a financial planner who works with seniors.

Get a BenefitsCheckUp. The National Council on Aging offers this online service to assist seniors in finding financial assistance for medication, food, utilities and other expenses. Visit benefitscheckup.org to get started.



DOCUMENTS YOU NEED

Whether or not your loved one wishes to continue to be involved in financials, it's important for another adult to know where all of these items are in the event of an emergency, to avoid unnecessary fees, expenses and financial difficulties.

- A durable power of attorney (for the caregiver)
- A living will
- A will
- Trust documents
- Stock and bond certificates, brokerage account information, annuities, CDs, life insurance policies and other investments
- Social Security, Social Security disability, pensions, 401(k) and other retirement benefits
- Loan agreements
- Health insurance policies, long-term disability insurance policies, Medicare records and prescription drug plan information
- Automobile insurance policies and titles
- Homeowner's insurance, deed and mortgage papers
- Recent billing statements (credit cards, utilities, subscriptions)
- Medical bills
- Tax records and forms

ASK THE EXPERT

WHAT IS A CAREGIVER CONTRACT?

Many caregivers use their own savings to pay for caregiving expenses. Some also reduce work hours or even give up a career. A caregiver contract, or personal care agreement, is a legal document that clarifies the relationship and the compensation the caregiver will receive for services. Learn more from the Family Caregiver Alliance at caregiver.org.

—JOHNS HOPKINS EXPERT JEREMY BARRON, M.D.

YOUR HEALTHY RELATIONSHIP

Focusing too much on caregiving can strain your relationship with the person you're caring for. Here's how to reconnect on a positive, personal level.

"WHEN YOU become someone's caregiver, it's important to maintain as much of your original relationship as possible," says Alicia Arbaje, M.D., M.P.H., a Johns Hopkins geriatric medicine physician. "You have to renegotiate roles and figure out how you are going to be together now." These tips can help you make rewarding connections.



Plan something just for fun. Regularly schedule time dedicated to doing something social together. Play a game, enjoy a meal out, share family stories over tea or go on an outing that's not an errand or medical visit.

Ask about activities. Maybe your loved one is an opera aficionado. If she isn't able to attend an opera live, watch one together on TV or a DVD. To find out what would be a nice fit, ask what your loved one would enjoy:

- What did you used to do that you miss?
- What would you like to do next weekend?
- What would you like to be doing more often?
- What would a great day for you look like?

Let technology help. If your loved one can't attend a graduation, wedding or other special event, record it digitally or set up a Skype session so she can watch it

in real time. You can also work together on a family tree or family history, using a computer to record stories and insights. "Even people who don't remember what they had for breakfast tend to retain the long-term memories," says Arbaje.

Reduce relationship friction. Many things can cause stress between a caregiver and patient. Sometimes a caregiver assumes responsibilities that the loved one isn't ready to relinquish or does them in a way that upsets the one being cared for. The key to harmony: Remember that you each have unique personalities. "The way you would do things isn't necessarily the way the person you're caring for would," says Arbaje. "Engage your loved ones in a discussion of how involved they are going to be in various aspects of their health care, and what they'd like you to do. This will help them feel in control." Bottom line: Ask your loved ones to tell you what they need from you, then do your best to abide by those wishes.

ASK THE EXPERT

HOW CAN I INITIATE CALM CONVERSATIONS ABOUT SENSITIVE TOPICS?

It's very confusing and overwhelming to talk to a loved one about things like when to transfer the paying of bills, driving a vehicle, or doing anything else that is important to her. Try to be sensitive while letting her know you'll be assisting more. You could say, "I know there are a lot of things you're dealing with right now. I'd like to know how I can help you with your finances." Another approach: Let a professional take the fall. I often tell caregivers to explain that a health care provider said they were concerned about this issue. That takes the emotion out of it. Or enlist the help of a case manager or social worker. Tell that person your concern and ask how to approach it without making your loved one feel that you're trying to take away her independence.

—JOHNS HOPKINS EXPERT

ALICIA ARBAJE, M.D., M.P.H.

CARING FOR YOU

These quick tips can help you be a happier, healthier caregiver for your loved one.

WHILE CAREGIVING CAN be tremendously rewarding, it can also be draining, both emotionally and physically. “Make sure that you have adequate time for yourself—for free time and for taking care of your own health,” says Johns Hopkins expert Jeremy Barron, M.D.

In fact, recent research underscores the benefits of a balanced perspective. A team of scientists led by Johns Hopkins experts looked at six years of health data for 3,053 caregivers and an equal number of non-caregivers. The surprising finding: Those who regularly tended to the needs of a family member enjoyed a nine-month extension of life expectancy—even if they felt some stress and strain. The researchers saw no differences in chronic health issues between the two groups. But experts say the key is healthy balance.

Remember: Flight attendants always instruct passengers to don their oxygen masks before assisting others. The logic is simple: You’re of no use to others if you’re unconscious. A similar analogy can be made for caregivers. You *must* make your own health and happiness a priority—for your sake and the sake of your loved one. It can start with these key areas of your life.



FITNESS

Take healthy steps. Walking for even just 10 minutes can make a difference in your day. Taking a walk can help you feel physically and mentally energized, clear your mind, boost your confidence, and improve your ability to perform everyday tasks, like lugging groceries and climbing stairs.

RELATIONSHIPS

Nurture friendships. A growing body of research has determined that social isolation is just as bad for health as cigarette smoking, high blood pressure, obesity and physical inactivity. Try this: Before each phone

ASK THE EXPERT

HOW CAN I AVOID BURNOUT?

It’s very important not to put yourself in a position where you’re going to get overwhelmed, stressed out, angry or resentful. Ideally, you want to identify a network of family caregivers and paid caregivers in the home who are able to take on some of the tasks that need to be done. You should also find resources for what we call *respite care*, which is simply care that gives the caregiver a break for a period of time, whether that’s a few hours or a few weeks. To find respite care services in your area, check out the ARCH National Respite Locator Service (archrespite.org), the National Adult Day Services Association (nadsa.org) or the Administration on Aging (eldercare.gov).

—JOHNS HOPKINS EXPERT JEREMY BARRON, M.D.

call you make or email you send on behalf of your care recipient, reach out to a friend with a call, email or even a quick text. Also plan a month's worth of get-togethers and put them on the calendar—now. These sessions can recharge and restore you more than you may realize.

HAPPINESS

Flip through old photos. In an interesting study from a telecommunications company, researchers discovered that people felt an 11 percent improvement in mood after looking at pictures from their past—that was a bigger boost than they enjoyed after

TRY IT!

Keep favorite photos on your smartphone or in your wallet to boost your mood.

eating chocolate, watching television, drinking alcohol or listening to music. Keep some photos on your smartphone so that personalized stress relief is always at hand whenever you need it.

SLEEP

Put worries to rest. If to-dos are making it tough for you to wind down, spend a few minutes making a list at least

two hours before bedtime, then set the notes aside—along with your stress—until you wake up in the morning. If you're not getting the seven to nine hours of quality sleep you need each night, supplement with one planned weekend nap.

NUTRITION

No time to eat right? That's not an excuse anymore! Try these super-fast options to stay energized throughout the day.

Sip a refreshing smoothie.

Blend together ½ cup skim milk, 6 ounces fat-free Greek yogurt, and 2 cups fresh or frozen fruit. Try blending in a handful of kale or spinach—it doesn't change the fruity flavor of the smoothie, and the greens give you a potent antioxidant boost.

Make a PB and B pick-me-up sandwich.

Peanut butter and sliced bananas on whole wheat bread is quick, delicious and portable. The bananas offer potassium and the nut butter packs magnesium—two energizing nutrients.

Enjoy a simply delicious salad.

Most of us don't eat enough vegetables on a day-to-day basis. Salads are an easy way to give your lunch or dinner a healthful produce boost. Once a week, gather your favorite salad ingredients and place them in individual containers. To make assembly quicker on particularly busy nights, buy cut leafy greens and vegetables and pre-cooked chicken or shrimp, or spend 30 minutes each week prepping these ingredients yourself, and enjoy fresh salads all week long.



QUICK EVERYDAY STRESS BUSTERS

When it comes to the main concerns of caregivers, managing their own stress comes second only to keeping their loved one safe. "If either the caregiver or the care recipient is having problems managing stress, it's important that they get professional help," says Johns Hopkins expert Jeremy Barron, M.D. "Talk to a geriatrician, social worker, case worker or psychotherapist about what you're feeling." If you're simply looking for ways to tame tension on your own, try these tips.

1. Breathe deeply for two minutes. Inhale quietly through the nose and exhale forcefully through the mouth.
2. Pray, meditate or repeat a positive phrase several times.
3. Take a yoga or other exercise class.
4. In a journal or notebook, write down the three best things that happened today.
5. Play with your pet or bond with a friend's furry pals.
6. Remember not to take hurtful behavior personally. If your loved one is lashing out, know that it may be related to illness, medications or frustrations.
7. Smile. The simple act can decrease feelings of anger.
8. Warm your hands around a cup of hot tea or coffee. Stress causes hands to become colder as blood flow is diverted toward your core; warming them tells your nervous system to settle down once more.
9. Eat some popcorn or another high-carb snack: The resulting boost in blood sugar will trigger feelings of calm. Even better: Eat it while watching a comedy show or movie.
10. Read other caregivers' stories online, or share your own. Check out the Family Caregiver Story Project on caregiveraction.org.

HELPFUL TECHNOLOGY

Smart resources can help you stay organized, in touch and informed as a caregiver.

WITH ALL THE ELECTRONIC TOOLS available to you, it makes sense to make the most of online resources.

SEARCH SMART

A recent study found that 72 percent of U.S. caregivers seek health information online. But take note: “Randomly searching ‘what do I do about this symptom’ is not such a good idea,” says Alicia Arbaje, M.D., M.P.H., a Johns Hopkins geriatric medicine physician. “You can’t be sure that all of the information you find will be safe.” Consider the source, and start with websites that have addresses ending in .org or .gov, such as healthinaging.org (American Geriatric Society’s Health in Aging Foundation), heart.org (American Heart Association), alz.org (Alzheimer’s Association), hopkinsmedicine.org and nihseniorhealth.gov (National Institutes of Health). Also ask a professional on your loved one’s health care team for recommendations.

SHARE NEWS

Is your loved one OK with sharing certain details of his health with others? With Facebook (facebook.com), you can create a page that is accessible only to people who have been invited to join the group. If possible, remember to ask the care recipient what’s permissible to share—and ask loved ones in the group what types of things they do and don’t want to know.

CREATE A SIGN-UP

Asking for help can be difficult. Getting people to commit to helping, even more so. Overcome both barriers by creating an online sign-up sheet where invitees can view a list of specific caregiving needs, then sign up for a particular task. A number of caregiver and organizational websites offer tools to help you create such a list.



ORGANIZE MEDICAL RECORDS

Online organizational websites are designed to help you collect, store, review and share health care information. Having your loved one’s medical information archived online makes it easier for you to access and share critical details during an emergency or at a doctor’s appointment.

KEEP AN ONLINE CALENDAR

Many websites offer account holders an online calendar, in which you can record your appointments and your loved one’s in different colors. They can even send you email appointment alerts with important details.

USE SMART APPS

If you have a smartphone, search for apps for your loved one’s pharmacy and insurance company, as well as those from condition-specific organizations such as the American Heart Association. Also download a fitness and nutrition tracker to help *you* stay in good health.

FOR MORE INFORMATION

HERE ARE A FEW MORE SUBJECTS, SITES AND ORGANIZATIONS WORTH VISITING ONLINE.

- Organizations for specific conditions that your loved one has
- Your local hospital’s website
- Your loved one’s health care providers’ sites
- Emergency response systems options
- Online support groups for caregivers or for people managing specific conditions