

YOU'RE NOT ALONE

This booklet is designed to provide basic answers to questions you may have about being a caregiver. It is estimated that there are some 40 million caregivers -- people who provide unpaid care to an aging parent, sibling, relative, friend or other adult -- in the U.S. at any one time. As the baby-boom generation continues to age, the number of caregivers will continue to increase.

HOW WE CAN HELP

The following information is designed to enable you to act as a caregiver on your own, to the extent you wish. When you need or want help, however, we are here. Capital Caring can assist you with compassionate, patient-focused care wherever necessary: in your home, an assisted living facility, a nursing home or virtually any other caregiving setting. We can provide support and care for any or all of the issues discussed in this booklet.

And when the level of caregiving needed exceeds what you want to or can do, Capital Caring provides customized, holistic hospice care. Capital Caring Hospice Services is one of the 10 largest nationwide, serving more than 1,000 patients every day.

Most people become caregivers because they want to do it, or because they feel obligated to. Either way, you don't have to do it alone. We are just a webclick or phone call away.



HOW DO I KNOW MY PARENT NEEDS MY HELP?

Assuming they don't simply ask for help, it's important to observe them closely for any changes that may signal that they are unable to deal with various aspects of day-to-day life. Here's what to look for:

Personal hygiene/appearance

- Not bathing, body odor.
- · Not dressing, staying in pajamas, unkempt appearance.
- Wearing the same clothes over and over.
- Not eating, spoiled food left in refrigerator.

Day-to-day activities/life maintenance

- · House/yard not cleaned or tended.
- · Mail not opened, bills not paid, medicines not renewed.
- Doctor and other appointments missed.

Personality/cognitive changes

- · Lack of drive or motivation.
- Failure to return calls.
- · Becoming verbally or physically abusive.
- Signs of depression: hopelessness, despair, lack of interest, crying, listlessness.
- · Having memory lapses.
- · Generally being confused.
- Difficulty performing familiar tasks.
- Misplacing things.
- Getting lost in normally familiar surroundings.
- · Displaying changes in speech.
- Exercising poor judgment. For example, falling for scams.

Physical Difficulties

- Mobility issues: difficulty walking, getting to the bathroom at night or to their car in
 the parking lot, climbing stairs, or using a walker or cane. Difficulty getting up from
 a seated position.
- Fatigue/Breathlessness: persistent exhaustion, even after a full night's sleep. Formerly simple
 tasks, such as picking up a purse or doing light housework, start to feel strenuous.
 Being frequently out of breath or requiring additional oxygen to breathe.
- Recurring or constant pain.

Potential Danger to Self

- · Bruises on body.
- Burn/singe marks on pots and other cookware (sign that they may be leaving food on stove and could cause a fire).
- New nicks/dents on the car (sign of decreasing ability to drive).

WHAT SHOULD I ASK THE DOCTOR?

There are several things you should do in advance to make sure that doctor visits are as beneficial as possible.

 Make sure you have the legal right to discuss your parent's health information.
 At the very least, you will need to have your parent's permission to talk to the doctor, either with them present



- or on their behalf. If your parent develops dementia or becomes otherwise cognitively compromised you may need a Durable Power of Attorney or a Health Care Power of Attorney in order to continue to act as their medical advocate.
- If possible, centralize your parent's medical care. Use doctors who all belong to the same medical group in order to make information sharing and trips to doctor appointments easier.

Organize all of your parent's medical data: conditions, treatments, prescriptions, doctors, insurance, etc. More and more apps for your smartphone are available that are specifically designed to help with this. Have this information available at the appointment.

Keep a diary of any new, troubling symptoms or behavioral problems that you've observed in your parent.

There are three basic questions you should ask the doctor, and continue to ask them as new developments arise and your parent's condition progresses:

What is wrong?

- Can you explain the diagnosis in more detail?
- · How common is this illness?
- How does this illness usually progress?
- Is my parent at further risk of injury or illness due to her condition?

What do I need to know?

- Are there any specific signs or symptoms we should look out for?
- Does my parent need to see another medical professional or specialist?
- What treatment do you recommend?
- How will my parent benefit from this treatment?
- What are the downsides to this treatment the possible negative side effects and impact on daily life?
- What are the alternatives if my parent chooses not to have this treatment?

What can I do to help my parent?

- How often should medication be taken and in what dosage?
- What side effects should we expect?
- What should we do if my parent misses a dose or takes an extra dose by accident?
- How soon should my parent have his next appointment?

Don't hesitate to ask your doctor about new or alternative treatments that you may have researched or heard about. He or she may disagree with these approaches, but you have the right to know why. And your suggestions may cause your doctor to reconsider or rethink his treatment recommendations in ways that will benefit your parent.

PREPARING TO BE A CAREGIVER

HOW DO I GET MY PARENT TO LISTEN TO ME?

Don't wait until a crisis occurs. The best time to talk with your parents is before they actually become ill. Your conversation with them can be a series of conversations that take place over a period of years. Waiting until your parent's situation has become serious is more likely to lead to emotional decisions made under stress, and lead to poor results.

Just start the conversation.

Look for an opening based on an article you might have read, an item in the news, or something your parent may have mentioned recently about their health.

Make sure your parent understands how your participating in their care will benefit them. For example: "My help will give you more time



to rest, or make it easier for you to remember everything you have to do."

Determine your parent's wishes and priorities. Your parent will be more likely to start working with you if you can identify one or two things that he or she wants to do, and that you can help accomplish. Stress the fact that you are partnering with them, not controlling them. "I understand that you want to have as much independence as possible. Let's talk about how we can do that."

Ask your parent's doctor to talk to your parent about issues on which they might resist you, but on which they would respect the doctor's expertise and authority. For example, the possibility that they may no longer be able to drive safely.

Do your homework first. Your conversation is much more likely to fail if it focuses solely on potential questions or problems that you and your parent foresee. Have some possible solutions already in hand that you can propose during your talk.

HOW DO I PREPARE MY HOME/MY PARENT'S HOME FOR CARE?

The home environment of someone who is receiving care is necessarily different from that of someone who is healthy and can live independently. Whether taking care or your loved one in your home or theirs, the surroundings have to be adjusted to provide maximum safety, comfort and independence.

HOW TO "FALL PROOF" YOUR HOME

No trip: Keep objects and furniture clear of pathways and walkways. Keep pets from underfoot.

No slip: Remove loose throw rugs or secure them with double-sided tape. Clean up spills immediately. Use non-skid mats or strips in tubs and showers to prevent falls. Install grab bars in showers, tubs and toilet areas to help with ease of movement and stability.

Safe steps: Have sturdy handrails on both sides of the entire staircase. Make sure all steps are in good repair. Replace loose, worn or broken steps. Firmly attach carpeting on all stairs if possible; if not use non-slip rubber treads.

Mobility. If your loved one has to use a walker, make sure they are fully trained in its use before allowing them to use it unassisted. They should know how to use the walker to sit down, stand up, turn and step down from or step up onto a curb.

General safety. Take measures to prevent the most common risks to elderly patients: falls, burns and other injuries caused by improper use of oxygen and other medical equipment; and medication overdoses and reactions. If your loved one lives with you, keep an intercom or baby monitor near so you can hear them when you are in another room.

Medication management. Know all of your loved one's medications, how and when they should be taken, and their potential side effects. Observe your loved one carefully for any adverse reactions. Store all medications as directed. Create a "medication safety zone" in the home: a dedicated area with adequate lighting and minimal distractions/ interruptions where all medications will be prepared and administered.

Emergency plan. Know what to do in the event of seasonal storms or natural disasters that require evacuation of a loved one. Maintain at least a one-week supply of medications at all times, as well as batteries and electrical generators for essential medical equipment. Program all emergency numbers into your cell phone. Arrange for an additional person to be trained as a caregiver if you are unable to do so.

As a caregiver, you may have to learn several new skills to help insure your loved one's medical and safety needs. These can include:

- · How to prepare and give injections.
- How to properly use oxygen tanks, hospital beds and other medical equipment.
- How to safely move your bed bound parent to a chair or out of the home in an emergency.
- How to perform CPR

A major consideration is preventing one of the greatest dangers to aging and elderly people: falling. At least half of all falls happen in the home. Your loved one's risk of falling increases with any of the following factors:

- History of falls (2 or more in the last 6 months).
- Medications (4 or more).
- Vision and/or hearing loss.
- Inactivity/decreased mobility/use of a walker.
- · Balance issues.
- High or low blood pressure.
- Foot pain/ shoe problems.
- · Mental status changes.
- Safety hazards inside or outside the home.



TAKING CARE OF YOU TOO

Caregiving is often rewarding but undeniably stressful. Most caregivers have jobs and families in addition to the person for which they provide care. It's very easy to burn out and even become ill if you don't make it a priority to include yourself in your caregiving efforts.

Don't feel guilty about taking time to care for yourself. You can't continue to care for your loved one properly if you burn yourself out or harm your health.

Get a two for one. Use your caregiver tasks as a way to care for yourself. For example, schedule a checkup for yourself the same day as your parent's doctor appointment. Take naps and rest when your loved one rests.

Use your benefits. See if your employer has a plan that helps employees find caregiver resources, such as community services, counseling and caregiver support groups. If your company has more than 50 employees, you may qualify for unpaid leave for work under the Federal Family and Medical Leave Act.

Plan time to prioritize your health. Caregiving can put you under prolonged stress, and that makes healthy habits even more important. Make yourself sit down and eat at least three meals a day. Make time to exercise, and get enough sleep.

Take a break. Resolve to continue doing the things you enjoy, and that will recharge your batteries drained by caregiving. Relax in a warm bath. Read a book or listen to music. Spend time with friends. Or just let yourself be alone for a short time.

Ask for help, and accept it when it is offered.

Cut yourself some slack. Being a caregiver means making difficult decisions and learning new skills that may not exactly match your abilities or interests. Accept that there will be difficulties and setbacks, but don't criticize yourself because of them.



TRANSITIONING TO HOSPICE CARE

How Do I Know When My Loved One Needs Hospice Care?

Hospice is care designed to meet the needs of those who are in the end stage of a terminal illness. Hospice care is advisable when your loved one has reached the point where managing his or her care exceeds your ability to provide the time and level of expertise needed to keep him safe, comfortable and as pain free as possible.

How Do We Talk About Hospice?

As noted earlier, the best time to talk to your loved one about any aspect of their care is before the need arises. Their wishes about hospice should be part of the overall plan you create together before or as they start to show signs that they may soon need care.



What Do I Need To Know About Hospice?

The most essential thing to understand is that quality hospice care is a coordinated effort between you and the hospice agency or organization. Capital Caring's approach builds on what you already have in place — for example, the private home or other facility where your loved one is being given care, and the medical providers that they already have — by adding a team of hospice experts.

These personnel can range from our expert hospice physicians and nurses to certified nurse aides, dieticians and social workers. Working together, and with your own doctors, they provide care that emphasizes pain control and the ability of your loved one to live as independently and as fully as possible in the final stage of life.

To learn more, please download and refer to our booklet on how to understand and make decisions about hospice care.

Call 1-800-869-2136 to speak with someone 24 hours a day, 7 days a week