

bridges
HOME CARE
A division of
Spectrum Generations

Assuming the role of caregiver



Bridges Home Care... caring for your loved ones for almost twenty years.

Assuming the role of caregiver

One of the most difficult things to deal with as a family caregiver for a parent, spouse, or other person is that gradually your roles will be different. You will assume new roles – financial, legal, household manager, and nurse.

There are millions of caregivers in the country, all facing similar issues and concerns. Your local area agency on aging can be an invaluable resource for information and services.

This booklet is intended to support you through this process and help you identify next steps.



*"There are four kinds of people in the world:
Those that have been caregivers;
those who are currently caregivers;
those who will be caregivers; and those
who need caregivers."*

– Rosalyn Carter

Who is a Caregiver?

YOU ARE A CAREGIVER IF YOU:

- Bring Dad a few groceries
- Take your wife to the doctor
- Help with bathing and dressing
- Remind Mom to take her pills
- Help with cooking or cleaning
- Help with bill paying

START CALLING YOURSELF A CAREGIVER:

Family members and friends who provide care to a loved one often think of themselves as daughters, husbands, partners, and friends – not caregivers.

Identifying yourself as a caregiver is the first, and often most important step, a person who is playing this necessary role can take.

WHY IDENTIFY?

Family members and friends who understand that they are caregivers:

- Gain confidence as they gain access to education and support
- Become part of a community of caregivers, while maintaining their role as wives, sons, partners and friends
- Provide the quality care they want for their loved



First Things First

One of the first things you should consider is making a plan of care. This doesn't need to be complicated or fancy. It will be an ongoing plan that you can refer to often and change as you and your family member's needs change.

The first questions to answer include:

1. Do you have family or friends that could assist if you were temporarily unable to provide care because of your own sickness or another emergency? Having a respite care provider in place is an important part of planning as a family caregiver.
2. Have you let your doctor know that you are a family caregiver? Family caregivers are at a higher risk for mental and 44physical illness. It is important your doctor knows that you are a family caregiver to help you limit your risk of illness.
3. Do you know about resources and support available to family caregivers? The Family Caregiver Support Program offers free trainings and support groups to unpaid caregivers of family members and friends. Contact Spectrum Generations at 1-800-639-1553 or via web at www.spectrumgenerations.org for more information on this program.
4. Does your loved one want you to be their Personal Representative for medical care?
5. Have you and your loved one completed the Durable Power of Attorney documents?
6. Will you provide all of the care or will you have other family members or paid staff help with care?
7. Is the home safe?
8. Have you thought about having a care management plan prepared by a professional? This can be a great tool for the family in determining what type and level of care your loved one wants. It may help set expectations for who can provide what support and when it should be reviewed.

Whenever possible, planning ahead can make your caregiving journey a little bit easier.



Powers of Attorney & Advanced Health Care Directive

Powers of attorney can bring peace of mind to both elders and their caregivers. Powers of attorney allow elders to empower a trusted person to make decisions about health care and finances on their behalf. Having such powers in place when a family member loses the ability to make their own sound financial decisions can be priceless, especially if the person in need of help denies or is not aware of worsening physical or mental health.

Understanding the Documents You Need

If the person you're caring for is still of sound mind (a little forgetful is okay, as long as they can understand the plans you suggest) and receptive to the idea of setting out medical wishes and naming someone to handle financial matters, that will make things much easier. You can help the person prepare and finalize both medical and financial powers of attorney. These documents will name someone, perhaps you, to oversee medical care and handle financial matters. Here's a brief overview of both documents.

Medical power of attorney. This document, often called a “durable power of attorney for health care”, names a trusted person to make health care decisions for someone who can no longer do so, or simply does not wish to. Depending on the person's state of residence, the health care representative may be called an agent, attorney-in-fact, health care proxy, health care surrogate, or something similar.

To make health care wishes clear, the person you're caring for can use a second type of health care document, often called a living will or a health care declaration, to provide written health care instructions to the agent and health care providers.



Financial power of attorney.

The financial power of attorney document you'll want to help your family member prepare is called a "durable power of attorney for finances." This document will let your family member or friend give someone else full authority to handle financial matters. The appointed person is usually called the "agent" or "attorney-in-fact," though he or she does not have to be an attorney.

The agent can handle mundane tasks such as sorting through mail and depositing Social Security checks, as well as more complex jobs like watching over retirement accounts and other investments, or filing tax returns. The agent doesn't have to be a financial expert, just someone who is completely trustworthy and has a good dose of common sense. If necessary, the agent can hire professionals to help out with complicated tasks.

An advanced health care directive, also known as living will, personal directive, advance directive, or advance decision, is a legal document in which a person specifies what actions should be taken for their health if they are no longer able to make decisions for themselves because of illness or incapacity. This is where your loved one can list the types of care they want continued, and the types of care they do not wish to receive.

If at some point a person is incapacitated a guardianship may be appropriate. It does not negate their free will. **A guardianship is the legal document required to make decisions that might be contrary to your family member's wishes.**

This can only be issued by a judge.

An attorney specializing in elder law can answer your questions and draw up these documents. Spectrum Generations, your Area Agency on Aging can give you names for referral.



Are your older relatives still managing ok?

How can you tell if a little extra help in the home might be beneficial? Some factors to consider:

- Are things moved to odd locations? For instance, are you finding non-food items in the refrigerator or perishable items in a closet?
- Are utensils or cookware put away dirty or with food particles stuck on?
- If driving, has their ability to react, and awareness of their surroundings diminished?
- Do they get lost in places that they have known well in the past?
- Are bills or correspondence building up more than normal?
- Even if the house appears tidy, are you noticing that it is getting increasingly dirty? Or do you notice unusual odors in the house?
- Have friends or neighbors expressed concerns regarding safety or health?
- Is personal hygiene becoming difficult; is their hair or clothing noticeably dirty, or do they have an unusual body odor?
- Are you seeing multiple purchases for the same items, or unusual purchases?
- Is taking medication on a regular schedule becoming difficult?
- Is your relative refusing to take their medication?
- Have you noticed unsteadiness or falls? Is there difficulty getting up after a fall?
- Are they unusually anxious or irritated?

All of the items listed above are indications that your loved one is having difficulty living independently and might benefit from having professional, in home help.



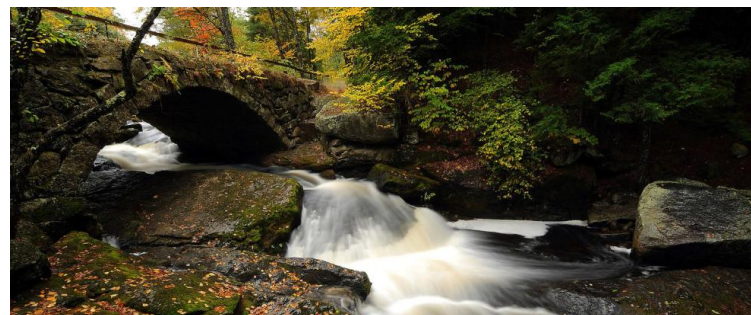
When considering whether having some help in the home is beneficial, it is time to decide what type of help. One of the decisions is whether to hire an independent, private caregiver, or to hire a person through a professional caregiver agency.

Some benefits of hiring privately are:

- You can select exactly who you want to hire. An agency will do its best to satisfy your needs and give a choice of people.
- You will have complete flexibility on what you have a person do if you hire privately. An agency will have a list of things that can be done and a list of items that their employees are not allowed to do. This is usually due to legal and insurance restrictions.
- Because the IRS considers you an employer, a privately hired person will usually cost less. The client (you) is directly responsible for deducting and filing the proper unemployment and social security taxes with a private hire. You are liable for any injuries or accidents that happen at your home with them.

Some of the benefits of an agency hire are:

- Caregivers are professionally screened, and the caregivers are usually certified by the state and bonded by the agency.
- All staff are thoroughly trained, and education is provided on a regular basis.
- Long-Term-Care insurance can be used to pay for the care. The cost of care may also be tax deductible.
- Twenty-four hour accessibility for services to maintain uninterrupted service.
- The agency is responsible for deducting taxes and providing benefits for the caregiver.
- A substitute person may be provided in the case of illness.



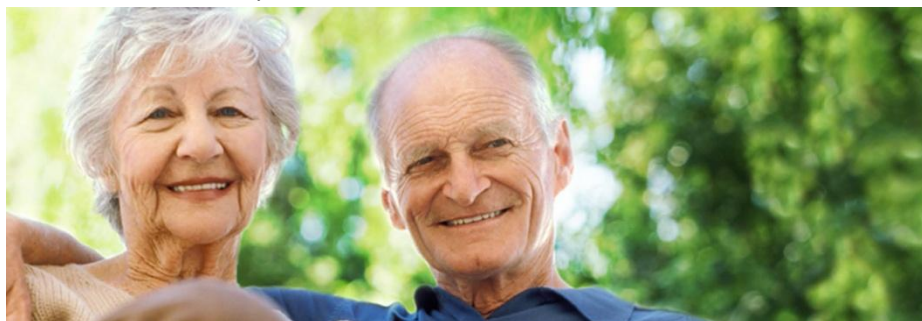
Starting Difficult Conversations

Is there a topic you dread having to talk about with your loved one? Maybe it's time to stop driving, to allow help managing medications, to have a conversation about a visit to a geriatric specialist, allowing help with the checkbook, or even that it's time to hire paid-for services in or around the home. No matter what the topic is, there are ways to make the conversation go a little smoother.

Starting the conversation:

- Talk in person if at all possible. As this topic is already difficult, try to have it face to face. This makes it more personal.
- If you don't have a close relationship, or you live far away and only have limited in-person time, you may want to write a letter.
- Outline the concerns you have and that you would like to talk about and help solve some of these issues.
- Introduce the topic openly and sincerely. Mention an article you read, or talk about someone else's situation. Then ask how they envision their lifestyle if they were faced with one of these tough decisions.
- The most important thing is to listen.
- This is a tough topic so give people plenty of time to digest the question and respond.
- Make the conversation about their wants and not about your plans.
- Keep your sense of humor. Let the conversation go where it goes, even if their answers aren't what you expected.
- If there is strain in the relationship or tough family dynamics, try not to let old habits or past hurts enter the conversation.
- Lastly, if your family member ignores the attempt to talk, ask why and let them know that it's something important that you want to talk about and keep trying.

Be gentle and persistent; even if the conversation doesn't go as well as you'd hoped, you'll at least have more information than you did before you started. You may also want to talk with a professional care manager to see if they can help.



Home Safety

Having a safe home should be one of the top priorities. As we age we don't raise our feet as high, we don't have the same peripheral vision, or the same balance. These suggestions, along with others, should be taken into consideration for home safety. One of the major concerns for an older person living in their home is the risk of falling.

- Remove any furniture that is not needed.
- Move any low tables that are in the way.
- Once the person in your care has gotten used to where the furniture is, do not change it.
- Make sure furniture will not move if it is leaned on.
- Add cushioning to sharp corners on furniture, cabinets, and vanities.
- Remove clutter and scatter rugs, which can cause trips and falls.
- Be sure stairs have even surfaces with no metal strips or rubber mats to cause tripping.
- Adjust or remove rapidly closing doors.
- For those who tend to wander, create a safe path through the home for a "wander loop."
- Plan for extra outdoor lighting for good nighttime visibility, especially on stairs and walkways.
- Place masking or colored tape on glass doors and picture windows.
- Place automatic night-lights in the rooms used by the person in your care.
- Use 100-to 200-watt light bulbs for close-up activities (but make sure lamps can handle the extra wattage).
- Put reflector tape on furniture and sharp corners.
- Use reflector tape to create a path to follow from the bedroom to the bathroom at night.
- Keep a telephone and flashlight where they are easily available.
- Clear fire-escape routes.
- Think about using monitors and intercoms.
- Turn the water thermostat down to 120°F or below to avoid burns
- Cover radiators with radiator guards.

What are your Options?

There are many types of support to help care for another as they age at home. Listed below are several different choices.

Informal help from a friend or neighbor – this could be someone who mows the lawn or who helps with some house cleaning. It can grow into more care, bathing and dressing.

Planning – An important consideration would be to create a Care Management Plan. This is a plan taking into account the financial resources, the medical considerations, and the support available. Think of it as a road map for care. Visit Spectrum Generations Bridges Home Care at www.bridgeshomecare.org for more information on this and other services provided by your area agency of aging.

Technology

Personal emergency response systems. Available from many sources at a variety of price levels.

Medication dispensing. These are devices that store and dispense medications on a scheduled basis. Some will remind the person, and some will even alert a third party if the medication isn't taken when it should be.

Remote monitoring. There are systems available that will keep track of a patient's schedule and remind them of tasks that need to be done. Some have cameras in the home that can be remotely



What are your Options . . . continued

Support professionals

PSS - A PSS (Personal Support Specialist) is a professionally trained person who provides non-medical support in your home. They can help with meals, personal care, shopping, or even just companionship. This level of care is usually available through agencies such as Bridges Home Care, who will make sure that the employees are a good fit for you, properly trained, licensed, and insured.



RN – This is a registered nurse. They can dispense medications, give injections, and educate patients about how to care for themselves. Specially trained RNs can also create a care plan and monitor the work of a PSS.

Adult day services – This is a licensed facility that provides a safe environment for a person needing continuous monitoring. Some provide meals and can dispense medications. These facilities can offer much needed respite for a caregiver, and social activity and contact for a loved one.

Caregiver Wellbeing

Caregiving can be a rewarding role, but most caregivers will eventually feel some degree of frustration, anger and guilt. These are all normal responses to an incredibly emotional journey. Often, caregivers put their needs aside, but it's important to make sure your own needs are met, as well.

As a caregiver, you may feel frustrated and overwhelmed with your chaotic life, or your lack of control over the disease's progression. Frustration often evolves into guilt. You may feel like there isn't a light at the end of the tunnel, and have the guilty thought, "how much longer can this go on?" Feelings can't be denied, but they can be changed to some degree by adjusting your perspective. For example, you may feel less frustrated with your loved one's behavior if you can remind yourself that they are not doing it on purpose, it is part of the disease.

Feelings can also be softened by certain self-care strategies. Journaling your feelings and daily relaxation techniques can be helpful. Identifying guilt triggers can also help. Does missing your child's activity because of your caregiving duties make you angry? Respite is a great strategy to reduce stress. Having someone come into your home to be a companion is one way to gain some respite time. Another is using adult day care. This is an option that should be considered if you are feeling overwhelmed. This safe environment will not only provide you with some time to do things important to you, it will provide the person you are caring for with social time, surrounded by people and activities designed to help them.

Remember, there is a difference between caring and doing. You may love. You may care. But at some point, sooner or later, you may not be able to do everything. Before that time arrives it would be good to have had the discussion about what comes next. Those moments when you cannot do everything may come in increments; today you may need a respite day and decide to send your spouse to day care for the day. A month from now, you may need to incorporate day care twice a week in your caregiving calendar. All of that is OK. The important thing is that you try and identify those moments, those limitations prior to actually being faced with them.



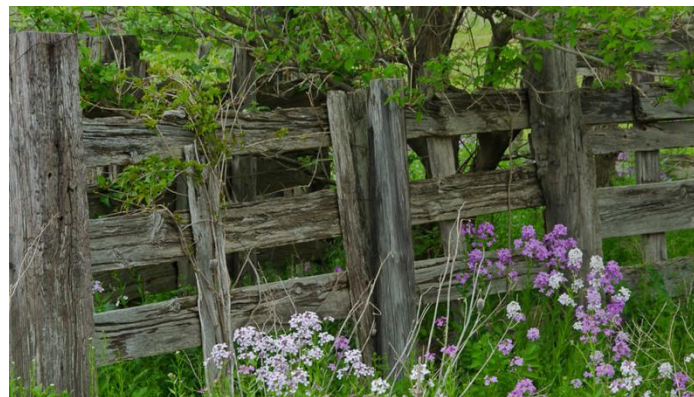
So how do you do that?

- First, find support. Spectrum Generations can help you locate a support group in your area, or www.alz.org offers online support groups if you can't find one near you. Share your feelings and gain others' coping strategies. It will help.
- Live in the day; focus on any positives from that single day. Look for a sign of your family member's remaining personality – perhaps a smile in hearing music – and connect with that.
- Prepare for, but don't dwell on the future. Don't just grieve for all the losses, but reflect on the good memories, maybe by sharing a photo album with your family member and others. Let go of unrealistic expectations. "I should never take time off to enjoy a movie with friends when it upsets Dad so much," is just not realistic in the long haul.

The bottom line is to listen to your feelings and know they are normal. Focus on the helpful and positive differences you have made in your loved one's life, not on the things you didn't do. And remember, as the disease progresses and you find yourself no longer able to have your love one kept at home, that isn't giving up, it is just a different way of caring.

Call Spectrum Generations and Bridges Home Care...
we can help with your caregiving journey.

www.bridgeshomecare.org 207-623-0761



Spectrum Generations is the Area Agency on Aging for Central Maine. We are the experts on Aging and Disabilities. As a non-profit social service organization we provide unbiased information, support, services, and education on issues that face the aging population. We have seven community centers throughout Central and Mid Coast Maine.

Some of the services we provide are:

- Information & Assistance
- Help with Medicare & insurance plans
- Meals on Wheels, home delivered meals
- Options Counseling
- Community dining in our centers
- SAVVY Caregiving Training
- Family Caregiving support groups
- Wellness classes
- Socialization



Through our Bridges Home Care division, we offer:

- Adult Day Care in four of our centers
- In-home personal care services
- Technology services – personal response units, medication dispensers
- Care management plans and services

Call us for help.

Spectrum Generations: 1-800-639-1553

Bridges Home Care: 1-800-876-9212

www.spectrumgenerations.org

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