

Dear Family Caregiver,

Yes, *you*.

If you're wondering whether the term "caregiver" applies to you, it probably does. A caregiver is anyone who helps an aging, ill, or disabled family member or friend manage their day-to-day lives.

It's a demanding job that can combine routine tasks with life-changing decisions. Your caregiving responsibilities might include checking in on a loved one each day, driving to medical appointments, helping with meals, or settling legal and financial problems.

The only thing you can know for sure about your role is that it'll change as your loved one's needs change.

Whether you expect to be a caregiver or not—and even if you've been doing it for years—it can feel overwhelming. As you scramble to make sure your loved one's needs are met, your own well-being can easily get lost in the shuffle.

That's where the AGIS Caregiver Kit comes in.

It provides simple, proven tips and tools that makes it easier to get started, for everyone involved. *Especially you.*

This kit is also our way of introducing you to AGIS. We hope you'll return to AGIS to get expert advice on tough decisions, connect with other caregivers in our forums, quickly find local products and services, learn from resources provided by National Caregiving Agencies and much more.



All the information we provide is free and unbiased.

Any time families gather, they have a great opportunity to start talking openly about caregiving. The need to provide care for a loved one can strain family relationships, or it can make them stronger. Honest communication usually makes the difference. This kit can help you start the conversations that can begin to make caregiving a team effort.

We at AGIS are here to help.

Sincerely,

Kevin Sypniewski
CEO, AGIS Network

Where to Begin Checklist

Directions: Use this list to help determine where you should start in helping care for a loved one. This is intended to help you create a checklist of tasks or things to learn more about in order to best take care of them.



Getting Started	Answer	Suggestions
What are your loved one's wishes and preferences?		<ul style="list-style-type: none"> • Meet with your loved one to discuss his or her current health situation and any prognosis. Identify how you will work together.
Do you know where all important documents and passwords are kept including bank accounts, retirement accounts, safe deposit boxes, investments, wills and trusts?		<ul style="list-style-type: none"> • Discuss the need for knowing the location of all records with your loved one. • Collect all files and documents you think you will need. • Complete a Personal Information and Record Inventory. • Obtain access to your loved one's safe deposit box or at least learn how you might get access if necessary.
Who else can help with caring for your loved one?		<ul style="list-style-type: none"> • Make a list of all the tasks with which you need help and then make a list of all the people who can help you (relatives, neighbors, friends, community resources). Ask for help. • Look into local caregiver resources that can provide respite care either in the home or at an adult day care facility. • Look into home-delivered meal programs such as Meals on Wheels.
What will you do to take care of yourself?		<ul style="list-style-type: none"> • Identify how you will find time for yourself each day to do something you enjoy. • Assess your own level of stress. • Join a support group. • Take care of your own health: eat well, get enough sleep, and exercise.

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Type of Care Needed	Answer	Suggestions
What kind of care does your loved one need now and how might that change in the future?		<ul style="list-style-type: none"> • Review different types of care. • Talk with your loved one about his or her housing preferences (e.g., wants to stay at home). • Complete <i>Assessing Your Loved One's Needs</i> checklist. • Consider hiring a Geriatric Care Manager to perform a formal assessment.
Could your loved one remain at home if he or she had some professional help (example: skilled nurse, home health aide)?		<ul style="list-style-type: none"> • Research the types of professional services available in the home. • Search local resources to find out which providers are available in your area. • Perform a Home Safety and Security Checklist to identify home improvements.
Would your loved one do well in an assisted living community?		<ul style="list-style-type: none"> • Research more about what features assisted living facilities provide. • Visit a few assisted living facilities.
Will he or she likely need a skilled nursing facility or nursing home in the future?		<ul style="list-style-type: none"> • Gather more information from his/her doctors. • Research and visit a few skilled nursing homes.
Has your loved one been diagnosed with a mental or health condition that might require specialized care?		<ul style="list-style-type: none"> • Gather more information from his/her doctors. • Research facilities that provide specialized care related to the diagnosis.

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Costs and Insurance	Answer	Suggestions
How much will it cost to provide care?		<ul style="list-style-type: none"> • Call providers of care to obtain estimates. • Estimate costs based upon expected length of stay and per day costs provided by facilities or professionals.
What do Medicare and Medicaid cover and is your loved one eligible for either or both?		<ul style="list-style-type: none"> • Review relative's Medicare coverage. • Research Medicaid eligibility criteria for relative's state.
What private health insurance does your loved one have?		<ul style="list-style-type: none"> • Locate relative's policy documentation or ID card. • Locate or order the relative's evidence of coverage from his or her health insurance carrier. Review coverage information.
Does your loved one have a long term care insurance policy? Does he/she need it?		<ul style="list-style-type: none"> • Locate relative's policy documentation. • Educate yourself about long term care insurance and obtain estimates for coverage for your loved one.

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Legal	Answer	Suggestions
Does your loved one have any advance directives in place?		<ul style="list-style-type: none"> • Locate your loved one's important documents. • Research advance directives and discuss options with your loved one.
Does your loved one have any power of attorney?		<ul style="list-style-type: none"> • Locate your loved one's important documents. • Learn about power of attorney and the procedures. • Get advice from an estate attorney. • Discuss options with your loved one.
Does your loved one have a will? If not, how can I help create a legally binding will?		<ul style="list-style-type: none"> • Locate your loved one's important documents. • Learn about power of attorney and the procedures. • Get advice from an estate attorney. • Discuss options with your loved one.
Is your loved one capable of making his or own decisions anymore?		<ul style="list-style-type: none"> • Get advice from an eldercare attorney or family attorney. • Discuss options with your loved one and other family members.
Has your loved one communicated any final wishes for after his/her death?		<ul style="list-style-type: none"> • Locate your loved one's important documents. • Learn more about funeral and memorial service options as well as cemeteries and cremation services. • Discuss options with your loved one.

Assessing Your Loved One's Needs

This checklist is intended to identify areas of concern that you may want to monitor more closely or gather more information about.



CAN YOUR RELATIVE ...	YES	NO	COMMENTS
Dress and undress without help?	<input type="checkbox"/>	<input type="checkbox"/>	_____
Drive or use public transportation on own?	<input type="checkbox"/>	<input type="checkbox"/>	_____
Shop for groceries or clothing on own?	<input type="checkbox"/>	<input type="checkbox"/>	_____
Prepare meals?	<input type="checkbox"/>	<input type="checkbox"/>	_____
Take a bath or shower without help?	<input type="checkbox"/>	<input type="checkbox"/>	_____
Get in and out of bed without help?	<input type="checkbox"/>	<input type="checkbox"/>	_____
Be left alone during day?	<input type="checkbox"/>	<input type="checkbox"/>	_____
Pay bills and manage finances on own?	<input type="checkbox"/>	<input type="checkbox"/>	_____
Clean the house or apartment?	<input type="checkbox"/>	<input type="checkbox"/>	_____
Manage household duties?	<input type="checkbox"/>	<input type="checkbox"/>	_____

Assessing Your Loved One's Needs

CAN YOUR RELATIVE ...	YES	NO	COMMENTS
Live alone comfortably and confidently?	<input type="checkbox"/>	<input type="checkbox"/>	_____
Remain active and interested in life and hobbies?	<input type="checkbox"/>	<input type="checkbox"/>	_____
Maintain a positive attitude?	<input type="checkbox"/>	<input type="checkbox"/>	_____
Walk, climb stairs and can get around the house easily?	<input type="checkbox"/>	<input type="checkbox"/>	_____
Care about own personal health and well-being?	<input type="checkbox"/>	<input type="checkbox"/>	_____
Manage own medications?	<input type="checkbox"/>	<input type="checkbox"/>	_____
Maintain a healthy weight?	<input type="checkbox"/>	<input type="checkbox"/>	_____
Take care of themselves?	<input type="checkbox"/>	<input type="checkbox"/>	_____

For any question where you answered no to any question, you should monitor that activity more closely or he/she may need additional care.

Suggestions:

- Talk with your loved one about your concerns to problem solve together or to ask for permission to speak with his/her physician.
- Consider meeting with a geriatric care manager to have a formal assessment performed.
- Look into home modifications and products that could help your loved one get around more easily.

Communicating with Your Loved One

Unless your loved one is unable to express his or her wishes, all decisions about his or her care should be done together. The following are some suggestions for how to communicate effectively with your loved one about care and quality of life.



- Prepare an agenda.
- Come up with a list of solutions to discuss.
- Set aside a time when neither of you will be interrupted.
- Start the discussion by sharing a story of a family member or friend who was in a similar situation.
- Speak clearly and stick to one agenda item at a time.
- Ask if he or she has already expressed his or her wishes with someone else or in writing.
- Be prepared for some negativity. Life changes are difficult for everyone.
- Have patience by allowing him or her enough time to express concerns, fears or feelings.
- Repeat back what you have heard to confirm understanding. Try not to make assumptions or jump to conclusions.
- Pay attention to body language and other nonverbal cues to get the full message.
- Be honest about medical prognosis, financial issues or your ability to help him or her.
- Express how you feel using "I" statements to show your concern. "I'm worried, ..."
- Encourage your loved one to be independent as long as possible.
- Consider using a third-party such as a social worker, counselor or care manager to facilitate the conversation.
- End the discussion as soon as one of you starts feeling tired or too angry to communicate effectively or arguing begins.
- Follow through on anything you have promised.

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Tips for Family Caregivers

- 1** Caregiving is a job and respite is your earned right. Reward yourself with respite breaks often.
- 2** Watch out for signs of depression, and don't delay in getting professional help when you need it.
- 3** When people offer to help, accept the offer and suggest specific things they can do.
- 4** Educate yourself about your loved one's condition and how to communicate effectively with doctors.
- 5** There's a difference between caring and doing. Be open to technologies and ideas that promote your loved one's independence.
- 6** Trust your instincts. Most of the time they'll lead you in the right direction.
- 7** Caregivers often do a lot of lifting, pushing, and pulling. Be good to your back.
- 8** Grieve for your losses, and then allow yourself to dream new dreams.
- 9** Seek support from other caregivers. There is great strength in knowing you are not alone.
- 10** Stand up for your rights as a caregiver and a citizen.

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Care Management Techniques You Can Use

Did you ever wish you could just pick up the phone and call someone who would take stock of your situation, help you access the right services, counsel you and your family to help resolve some of your differences, then monitor your progress with an eye toward channeling your energy and abilities as effectively as possible?

If your answer is “yes,” you’re not alone. Having the help of a care coordinator (often called a care manager) could make all of our lives easier and less lonesome, and help us be more capable family caregivers. While most of us may not have access to a care coordinator, we can all learn how to think and act like one, thereby reaping numerous benefits for our loved ones and ourselves.

What Is Care Coordination?

Although every case is different, the care coordination approach usually involves:

- Gathering information from healthcare providers;
- An assessment of your care recipient and the home environment;
- Research into available public and/or private services and resources to meet your loved one’s needs; and
- Ongoing communication between all parties to keep information up to date and services appropriate and effective.

Unfortunately, an assessment of your abilities and needs is not necessarily a standard part of the process, but it should be. A complete view of the situation cannot be gained without one. An objective analysis of your health, emotional state, other commitments, etc., are key elements in determining how much you can and cannot do yourself, and what type of outside support is needed to ensure your loved one’s health and safety.

Become Your Own Care Coordinator

By learning and applying at least some of the care coordination techniques and ideas that follow, you’ll be in a much better position to develop an organized course of action that will, hopefully, make you feel more confident and in control — a goal well worth working toward.

Educate yourself on the nature of the disease or disability with which you're dealing. Reliable information is available from the health agency that deals with your loved one's condition and the National Institutes of Health. When using the Internet, stick with well-known medical sites. Understanding what is happening to your care recipient will provide you with the core knowledge you need to go forward. It will also make you a better advocate when talking with healthcare professionals.

Write down your observations of the present situation including:

- Your loved one's ability to function independently, both physically and mentally.
- The availability of family and/or friends to form a support network to share the care.
- The physical environment: Is it accessible or can it be adapted at reasonable cost?
- Your other responsibilities — at work, at home, and in the community.
- Your own health and physical abilities.
- Your financial resources, available insurance, and existence of healthcare or end-of-life documents.

This assessment will help you come to a realistic view of the situation. It will let you know the questions to which you need answers. It can be a handy baseline for charting your caregiving journey and reminding you just how much you've learned along the way.

Hold a family conference. At least everyone in the immediate family should be told what's going on. A meeting can set the stage for divvying up responsibilities so that there are fewer misunderstandings down the road when lots of help may be needed. A member of the clergy, a professional care coordinator, or even a trusted friend can serve as an impartial moderator. A family meeting is a good way to let everyone know they can play a role, even if they are a thousand miles away. It can help you, the primary family caregiver, from bearing the brunt of all the work all of the time.

Keep good records of emergency numbers, doctors, daily medications, special diets, back-up people, and other pertinent information relating to your loved one's care. Update as necessary. This record will be invaluable if something happens to you, or if you need to make a trip to the ER. If you can maintain a computer-based record, that will make updating all that much easier and it might even allow you to provide the medical team with direct access to the information.

Join a support group, or find another caregiver with whom to converse. In addition to emotional support, you'll likely pick up practical tips as well. Professionals network with each other all the time to get emotional support and find answers to problems or situations they face. Why shouldn't family caregivers?

Start advance planning for difficult decisions that may lie ahead. It's never too early to discuss wills, advance directives, and powers of attorney, but there comes a time when it is too late. It is also vital that you and your loved one think through what to do if you should be incapacitated, or, worse, die first. It can happen.

Develop a care team to help out during emergencies, or over time if your situation is very difficult. In an ideal world there will be lots of people who want to help. More likely you'll be able to find one or two people to call on in an emergency or to help with small chores. The critical thing is to be willing to tell others what you need and to accept their help.

Establish a family regimen. When things are difficult to begin with, keeping a straightforward daily routine can be a stabilizer, especially for people who find change upsetting and confusing.

Approach some of your hardest caregiving duties like a professional. It's extraordinarily difficult to separate your family role from your caregiving role, to lock your emotions up in a box while you focus on practical chores and decisions. But it is not impossible to gain some distance some of the time. It requires an almost single-minded approach to getting the job at hand done as efficiently and effectively as possible. It takes practice, but is definitely worth the effort.