



CAREGIVER TOOLKIT

*SUPPORTING YOU ON YOUR JOURNEY AS YOU
CARE FOR YOUR LOVED ONE.*

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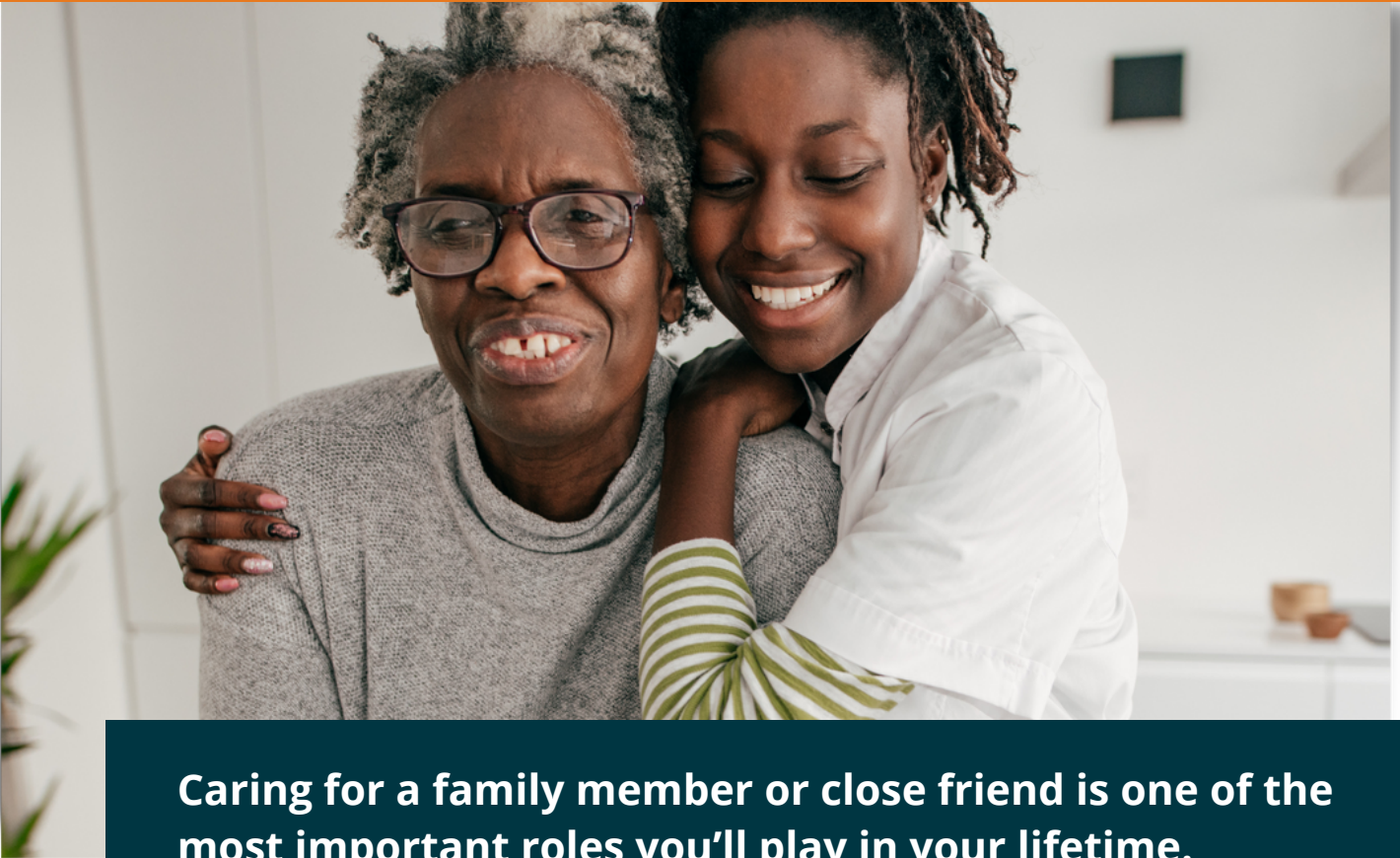
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Refer to JABA's **My Caregiving Plan & Level of Care Assessment** tools to further support your journey.

INTRO TO TOOLKIT



Caring for a family member or close friend is one of the most important roles you'll play in your lifetime.

Caregiving may start with taking your loved one shopping or to the doctor. Later, you may begin taking time off work, cooking, or paying bills. No matter where you are on the journey of caregiving, having a good plan to help guide both you and your loved one will make the process easier.

This guide is a practical tool to help you care for your family member or close friend. You'll find information, resources, and checklists to help you get organized and find support you may need.

Remember, you don't need to do this alone. JABA is here for you and your family every step of the way as you build a network of support.

Each step you take gathering and organizing information is building your resource toolkit.



5 STEPS FORWARD

This guide has five important steps that will help you on your journey.



Start the conversation. Many people wait until a crisis before they talk about their values, wishes for health care, or details of their finances. If you wait until a fall, accident, or diagnosis, you might have to guess at what your loved one wants.



Form your team. No one should try to handle caregiving alone. While other family members are likely to help, do not overlook friends, coworkers, clubs, or religious and other organizational membership as resources too.



Make a plan. A caregiving plan will help you respond quickly and effectively if a need comes up. It can also give peace of mind. A plan helps everyone get on the same page and keeps the focus on what's best for your loved one.



Find support. Issues may come up during caregiving. You may need more information and support. Reach out to organizations and professionals with experience in helping caregivers.



Care for yourself. As a caregiver, it is easy to forget about your own needs. You must keep up your energy and stay as healthy as you can in order to care for others. It is just as important to make a plan to take care of yourself as it is to create a caregiving plan.

“The future is not something we enter. The future is something we create.” — Leonard I. Sweet, *author and minister*

#1 START TALKING



Your loved one might be looking for a chance to talk about these topics too. By starting a conversation, you are helping them open up.

A lot of uncertainty can be avoided if you talk with your loved one before something happens. It's easy to put off these conversations because they can be difficult. Plus, we're busy. It never seems like the right time to bring up what we think will likely be an uncomfortable topic. Look for an opening.

Try not to anticipate what your loved one might say or how they will react. Just get the conversation started. It will likely take place over time. Be open. **Express your love and concern and, most importantly, listen.**

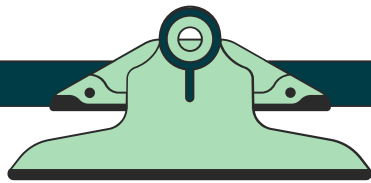
Conversation Starters:

1. **"I just read an article** about gathering all your important papers. Sometime can you show me where yours are and what you'd like us to do just in case?"
2. **"As time goes on, do you think** you will want to stay in this house? It might be difficult with all the stairs."
3. **"You mentioned** your eyes are bothering you. Is this causing problems with reading or driving?"



Respect your loved one's wishes. Every caregiving plan must focus on the wishes of the person receiving the care. A plan should always be made with the involvement, knowledge, and consent of your loved one. A person with dementia or other brain changes should participate as much as possible.

Once you have started the conversation, you may wish to bring in a few other trusted family members or friends to be part of the process.



Before Meeting Consider:

- Who is the best person to start or lead?
- What are your own feelings and outlook?
- What are your goals or what is the best outcome as a result?
- What are you prepared and not prepared to do?
- What is most difficult for you about this conversation?

It is important to have a leader to keep the process moving. They also make sure people understand what has been decided. In most families, one person takes the primary role because he or she lives nearby, has a close relationship, or simply is a take-charge person. There may be conflicts, but do not be afraid to talk through them. Better now than in a time of crisis.

It is also sometimes helpful to engage an outside facilitator, such as a social worker or minister. They can keep everyone focused, manage potential disagreements, and share difficult subjects during the meeting.

JABA Aging Services Coordinators can help facilitate these discussions.



“Caregiving often calls us to lean into love we didn't know possible.” — Tia Walker, author of *The Inspired Caregiver: Finding Joy While Caring for Those You Love*

Size up the situation. Figuring out what your loved one’s priorities are will help you determine the next steps. It can lead you to find support ahead of time. Your loved one may be hesitant to share details of their finances or health, but approach them with respect and explain your reasons.

Review finances. Money can be a sensitive subject, but it is often at the heart of many choices. Health insurance, including Medicare, pays for little, if any, of the costs of care in a nursing home, assisted living residence, or help with daily activities. Ask your loved one to review their bank accounts, investments, insurance coverage, and loans. Find out if they have long-term care insurance and funds or assets that can be used to cover potential care needs. Remember that many programs have financial assistance or scholarships available. Try not to get discouraged. You are gathering the information you need to move forward to get supports in place.

DID YOU KNOW?

Medicaid will pay a family member or friend to provide care for their loved one.

Counter resistance. Your loved one might say, “I just don’t want to talk about it.” Some people are private. It is also hard for some people to admit they need help, especially if it’s from their children. If your first conversation doesn’t go well, try again. Start by talking about just one part of your concerns. If your loved one shuts you out, ask a trusted friend, doctor, or faith leader to approach them. Or encourage them to work with an **Aging Services Coordinator at JABA** who can help them talk about these topics on their own terms.

#2 FORM YOUR TEAM



Caring for a family member or friend is too big of a job for one person.

Trying to do everything yourself may lead to burnout and problems with your health and well-being. Instead, reach out to form a larger network of friends, family, and community resources that can help you with your loved one's care. Your loved one can help you find willing members that you may not have thought about, such as neighbors or friends from their faith community.

Look for team members. Team members do not need to all live nearby or have lots of time to help. Family or friends living at a distance or with limited time can pitch in behind the scenes with meal organizing, bill paying or financial help. You may feel hesitant to ask others for support, but some people may feel left out if they are not asked. They might just need a little encouragement to take on a task.

Find programs and services. Just because they are not family, does not mean they cannot be part of your team. Many programs and services exist to support seniors, adults with disabilities and caregivers. Even help in one area can have big impacts on quality of life. **JABA's Senior Helpline** (434-817-5244 or toll-free 833-559-2428) has information about services.

CONSIDER THIS

Building a team of support not only helps you manage your loved one's needs, but it also supports your loved one by providing them a larger social network.



#3 MAKE A PLAN



By now, you should have an idea of the caregivers on your team. Now you can figure out a plan. The best caregiving plans are made with the input of the person you are caring for.



You can start exploring options in the community and bring in team members to help manage the workload. Be sure to ask your caregiving team members about which tasks they would like to do. Assigning tasks can take place in a family meeting, over a conference call, or through a series of emails.



The plan should include immediate needs as well as future needs, but the plan does not have to be long or fancy. You can never plan for every detail or situation.



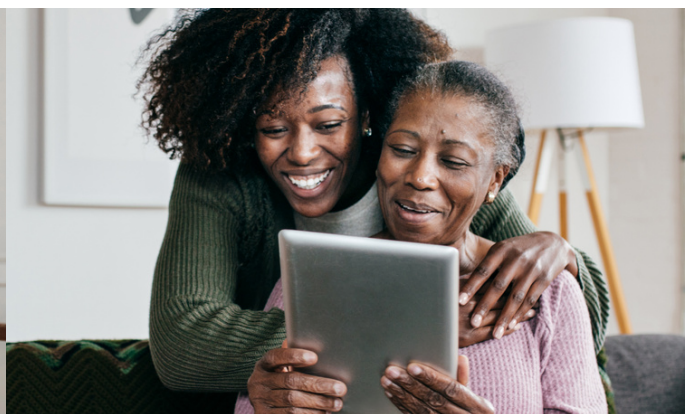
Options for meeting needs will depend on finances, willingness of your support team, and community resources and services. For example, if your loved one wants to move in the next year, you can assign someone the task of researching locations. Someone else might offer to spend some weekends helping sort through belongings.



Set up a system for sharing with everyone on the team. A written summary of the plan can organize your loved one's wishes and needs. The point person should be a detailed planner who can work through conflicts between the team members. There are many ways people can help. For example, you might want someone outgoing to talk with medical staff or insurance companies.



Be open to changes in the situation and team members' ability to help. Your loved one's needs may change from what you expected.



#4 FIND SUPPORT



It's okay to reach out for more help. If the needs are more than what your team can do, or you are not sure what to do, you could get help from an organization in your community.

Find community resources. JABA can help you find services like home delivered meals, transportation, respite centers, care management, and more. Explore **JABA's programs and services** (jabacares.org). And check out **Seniors & Caregivers Resources** (jabacares.org/senior-caregiver-resources) to find more services and support in your area.

Talk to a professional. A loved one's needs can be complex, like when health, emotional, and financial problems are involved. A nurse or social worker can help you know what is needed, find help, and arrange and monitor care. Your job may have an employee assistance program that can help find services in your community.

Learn about options to age in place. Organizations and services help seniors age where they want, like in their own homes or with family. Explore options by calling **JABA's Senior Helpline** (434-817-5244 or toll-free 833-559-2428). Learn more about **Respite & Enrichment Centers** where members are engaged, included, and valued, letting them live with family longer.

"Courage is the power to let go of the familiar."
— Raymond Lindquist, *minister and author*



Ask about licensing, background checks, training, and costs when hiring help.

Hire help. If you see that your loved one needs help with daily tasks, you can explore a range of home care services available. Some home care workers do housekeeping, cooking, laundry, and shopping. Others give more hands-on help with bathing and dressing. They can sometimes help your loved one move positions, which usually requires special training, a license, or certification. **JABA's Aging Services Coordinators** can help you find the right services and connect you with providers. They can also help you see if you qualify for publicly funded services or financial assistance. You can contact home care agencies or do a search for private caregivers in the area ([care.com](https://www.care.com)).

Find housing with support services. Your loved one may decide that they would prefer to get care in a new home that combines housing with support services. You can look into housing options in your community. Make a list of what your loved one wants or needs in a new home, like location, group meals, laundry service, and more. Not all types of housing are available in every community.

Once you know the type of housing your loved one wants, visit several facilities, and be sure to talk with residents and their families.



Not sure what type of housing would be best?

Use the **Level of Care Assessment** tool to get an idea of what type of care your loved one needs. Consider asking JABA for a one-on-one meeting to understand your family's needs.

#5 CARE FOR YOU



Remember caregiving impacts you. Balancing caregiving with work and other family needs can be stressful. When asked, family caregivers often say the most difficult part is the time it takes. Stress can hurt your health, well-being, and ability to give care. Make regular time for what is important to you and get help.

Caregiving at a distance. Giving care when you do not live in the same area can be time consuming, expensive, and frustrating.

Long-Distance Caregiving Tips



- **Social workers, nurses and other professionals** can help with choices and care options.
- **Technology** can help, like medical alert systems, health tracking devices, phone apps for medical notes, and calendar reminders.
- **Organizing** your caregiver plan is helpful to stay on track.
- **Keep all contact info** for doctors, insurance, and neighbors.
- **Keep a list** of their medicines with you.

Work and caregiving. Many of those who are caring for a loved one also work. Find out if your job has policies or programs to support caregivers. Benefits or services may help make things easier. Think about using flextime or work from home to free up time. If you need more time off, consider asking whether you are covered by the **Family and Medical Leave Act**. Many people are covered by the act, but if you work for a small company or haven't worked for your employer long, you may not qualify for this program.

Understand the impact on finances. Your personal finances can take a hit from family caregiving. Things like time off work or passing up promotions and/or buying groceries and prescriptions can hurt your budget. Try to understand these costs. If you can, keep working to increase retirement income later.

Advocate for you. Let your loved one's doctor know that you are their primary caregiver. Tell them you need to know about your loved one's condition and the treatments given. Ask for training if you need to do health care at home. Some doctors might be hesitant to share information. However, most healthcare offices have a form you and your loved one can sign giving doctors permission to talk about care with you. If your loved one has a durable power of attorney for health, be sure his or her doctors have a copy in their files.

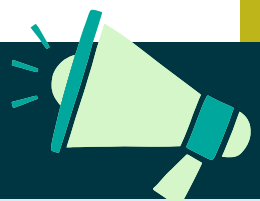
The Caregiver Advise, Record, Enable (CARE) Act requires hospitals to:

- Provide patients the chance to assign someone as their caregiver when admitted.
- Inform you when your loved one is going home.
- Give you instructions on the health tasks done at home, like taking medication, wound care, and transfers.



Learn more about the CARE Act and **get your free wallet card** (aarp.org/walletcards) to keep with your insurance card, so you have important information about the CARE Act when you need it.

10 Tips to Advocate for Yourself



1. Set boundaries with family, friends, and health staff.
2. Introduce yourself as a caregiver to health staff.
3. Ask for help.
4. Reach out to organizations that can support older adults, caregivers, and those with your loved one's diagnosis.
5. Reach out to a **State Ombudsman** for advocacy support for loved ones in assisted living or nursing housing.
6. Seek counseling or therapy for yourself.
7. Know your rights as a caregiver through the CARE Act.
8. Take care of your own needs, so you can keep caring for others.
9. Share your feelings with a caregiving support group.
10. **Give yourself credit. You are doing an incredible job, don't forget that.**



RECOGNIZE

Understand your emotions. How you became a caregiver can impact how you feel about the experience. Maybe you have always been close to your loved one, and you see this as your chance to give back the loving care they gave to you. Maybe you have been pushed into caregiving and feel hurt because you are stretched with your own work and children. Regardless of how you arrived to this role, what you are feeling is normal and valid.

Professional therapy can help you understand and process your response to caregiving in healthy ways. Services can often give therapy for free or at a reduced cost. Do not let cost be a barrier to reaching out for help. **RegionTen** (regionten.org) & **The Women's Initiative** (thewomensinitiative.org) have mental health services that may help you or a loved one.

Take care of yourself. Allow yourself to take a break. Take time for your own needs for exercise, sleep, and healthy eating. Find ways to reduce stress and make sure to find time for fun! If you care for yourself, you often return to caregiving renewed and better able to give care for your loved one. To cope, consider connecting with social networks like **CaringBridge** (caringbridge.org), **AARP's online caregiving community** (aarp.org/caregivingcommunity), and **JABA's Caregivers Facebook group** at (facebook.com/groups/jabacaregiversgroup).



CARE

Many caregivers struggle finding time for themselves, especially when their loved one needs care 24/7. **Respite & Enrichment Centers or Companion Support Services** may give your loved one more engagement and friendship, while freeing up your schedule.

Caregiving services and support groups. There is comfort knowing others have the same ups and downs as you. It may also give you ideas about other strategies and resources available to make things easier. You can find local support groups through **JABA** (jabacares.org) and **Eldercare Locator** (eldercare.acl.gov). A variety of support groups are hosted at places like **The Center** (thecenterville.org).



SUPPORT

Being a caregiver means giving yourself care too.

Don't feel guilty for having your own needs. Remember that your loved one will also benefit from having a wider circle of care. When you are burnt out and stressed, it impacts the care you can give your loved one. This does not mean you are a bad caregiver. Everyone needs to show up for themselves before they can show up for someone else. When you take the time, resources, and support you need, it means that you are supporting your loved one the best way you can.


YOUR NEEDS AS A CAREGIVER

Caregiving is a 24/7 responsibility and often caregivers are first to stop taking care of their own needs to be there for their loved ones. Check in with yourself to see how you are doing and if you are giving your own needs enough attention.

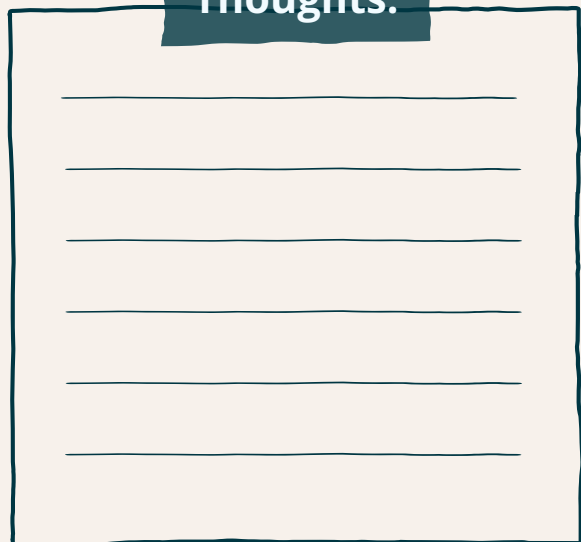
The following are all signs that you may need more support, and JABA is ready to help you and your loved one for a sustainable life for you both.

- Feel that I have to do everything myself.**
- Feel like I'm never doing enough.**
- Feel guilty that I'm not able to meet all my obligations all the time.**
- Worry about the safety of my loved one.**
- Given up things that I enjoy.**
- Put off taking care of myself, including my own health.**
- Concerned about making critical mistakes in care decisions.**
- Worry that I'm not able to provide the care that my loved one needs.**

**Other
Feelings:**



**Other
Thoughts:**



Remember you are not alone. JABA can give information about support groups, respite, and other supports to help on your journey. Continue to the next page to think about how you can start caring for yourself.

CARING FOR YOU

You must care for yourself to be able to support your loved one. Think about how you could love yourself in each of these ways. If it is hard scheduling time for yourself, reach out to your support system for help. Call JABA to learn about programs and services that can provide you respite and your loved one engagement.

PHYSICAL SELF-CARE

- _____
- _____
- _____

PHYSICAL SELF-CARE

examples

- Move my body (walk, stretch, etc)
- Nourish my body with full meals.
- Rest my body (sit, deep breathe, etc).

EMOTIONAL SELF-CARE

- _____
- _____
- _____

EMOTIONAL SELF-CARE

examples

- Call a friend to share how I'm doing.
- Schedule therapy.
- Do something I enjoy (read, movie, etc.)

INTELLECTUAL SELF-CARE

- _____
- _____
- _____

INTELLECTUAL SELF-CARE

examples

- Join a caregiver support group.
- Learn something that interests me.
- Share interest with a friend.

SELF-CARE NOTES