

Creating a caregiving plan is a positive step that can help ease stress — and caregivers often say that they wish they had thought about it sooner.

There may come a point when juggling the responsibilities and challenges of caregiving will be difficult. Consider how you can reach out for assistance.

Asking for Help

Caregivers frequently say it is hard for them to ask for or accept help. Asking for help is *not* a sign of weakness or shirking your duty. Trying to do everything on your own takes a toll that in the long run may make it more challenging to provide care.

People are often quite willing to help, for many reasons:

- People who care about you feel less helpless when they can lend a hand. Your friends and family can't cure cancer, but they can lighten your load.
- Some chores might not require much extra time. For example, everyone needs to shop for groceries, so it may not be hard for someone to help with shopping. Similarly, your neighbor might not mind mowing your lawn or shoveling snow when needed.
- You've helped others during difficult times, and they're glad to help you, too.

Getting Started: Creating a System of Support

If friends asks how they can help, be prepared with specific needs, or with a firm promise that you'll call them in the future for assistance. Often, people close to patients and their families want to help out, but don't know how to ask. They also may not know what you need or how to be helpful. Being specific lets others know clearly what is going to be useful and how they can step in. The more specific you are, the more likely you will be able to check something off your list. (*To help you get started, refer to the **Addendum: Checklist of tasks and needs** near the end of this document.*)

You may find it useful to make requests by e-mail, to allow friends and family time to plan and check schedules before responding. E-mail may also help you ask if it seems hard to do so in person.

Why Create a Plan?

Creating a caregiving plan can be good for you, your loved one, and others. Here's why:

- It gives you time to take care of your own health.
- Your loved one may be relieved that the burden isn't all on you.
- Other people may have time and skills that you don't have.
- With support from others, you can focus on tasks or needs that are most important to you and the patient.

Other options for help

If you need help, but feel uncomfortable asking for it, consider these tips:

- Ask a friend or a member of your family or faith community to request help on your behalf.
- Seek advice from a social worker, counselor, your faith community, or support group.
- Reach out to community agencies and other organizations.
- Consider hiring someone for tasks you can easily delegate or that are most essential. Maybe you can get help with day-to-day needs (such as grocery delivery), which can allow you to have some time to yourself or with the patient.

What if someone can't (or won't) help?

It may surprise you to see who steps up to the plate. Some people will make unexpectedly generous offers of help, while others you thought you could rely on may not come through.

It may help to understand people's reasons for declining an invitation to help with certain tasks or to help at all.

- Perhaps someone who says "no" to babysitting would prefer to help with another duty, such as picking up your dry cleaning.
- Maybe it's too painful for a close friend to see the patient ill.
- It may be too scary for a friend with a family history of cancer to be involved in a cancer patient's care.
- Maybe they are having their own hard time.

If close friends and family explain their reasons for saying no, it provides an opportunity for dialogue and understanding. But they may not want to talk about it or feel awkward about their inability to be involved.

If the reactions of others are distressing and you need to vent, find someone you trust who can listen and may be able to help you sort out your thoughts and feelings. If you have to speak up directly, do so. You can also decide to put these issues aside and re-examine the disappointment in these relationships at another time.

Keeping It Together: How to Stay Organized

Consider asking a friend to serve as a caregiving coordinator for you. This person can reach out to your contacts when no one has volunteered for a task, or make sure that people on dinner duty don't all bring lasagna.

Take advantage of online resources

Consider using the Internet for broader communication (including messages from you, and from others to you) and for assistance with a range of needs. Web sites such as www.lotsahelpinghands.org or www.caregiverhelper.com can help. Explore these free, secure, Web-based systems for organizing your caring circle of family, friends,

neighbors, and colleagues. You can also use these sites to share information, provide updates, add photos, and more.

The nonprofit CaringBridge (www.caringbridge.org) offers a free, secure online service that lets you create a personal Web site to send health updates, write journal entries, and display photographs. Visitors to the site can keep up to date on a patient's condition and write messages of support.

Some families create caregiver schedules using a **Google calendar** or social-networking sites like **Facebook** and **MySpace**.

Organize meal prep and delivery

Offers of meals or food are wonderful, but need some management to make a positive experience for all involved. The following ideas come from caregivers and patients who want to share what worked well for them.

Caregivers can serve as their own coordinator. If that responsibility is too difficult, consider asking a friend or family member to **organize a meal plan**. Here's what's involved:

1. **Identify friends, family, and neighbors who may want to help organize a "food chain."** Five or six is a good start. Depending on the needs of the family, how often meals may be needed, and for how long, you will need enough helpers for a rotation.
2. **Contact the identified people to see if they are willing to participate.** If you are comfortable doing so, ask the identified people if they know of anyone else who might be willing to join.
3. **Create a weekly or monthly schedule (on a calendar or similar format that works for you).** To start, one volunteer might deliver a full meal once a week, but, as time goes by, the list of volunteers could grow – and usually does, depending on the situation. One patient shared that she's seen a list comprised of 36 volunteers. These people delivered a meal just once every 6 weeks!

"[My wife] Kate was busy being my advocate, but I think caregivers need advocates of their own – someone to look for signs of burnout, to provide practical support, a diversion, or simply caring companionship."
—Joe, a patient with bone cancer

Questions to ask about meals and food delivery

- Any allergies or other dietary issues (lactose intolerant, vegetarian, etc.)?
- Favorite foods?
- Dislikes?
- Picky kids?
- Does drop-off time matter? If so, what time is best to drop off?
- What days are needed?
- Just dinners, or are other meals needed?
- Would the family prefer groceries only (instead of fully prepared meals)?
- Where should food be dropped off?

The volunteers

Once the list of volunteers is in place, each individual can be called in advance to schedule dinners. Scheduling one month at a time on a master calendar provides peace of mind for the patient, family, *and* coordinator! How often each volunteer prepares a meal depends on the number of volunteers. It may be once a week, every six weeks, or whatever works.

Food delivery

Select a convenient drop-off spot, such as a porch or open garage, so that the patient and family won't need to be disturbed each time someone brings food.

- Consider using a large cooler that can hold food drop-offs.
- Volunteers should bring food items in disposable containers (not dishes that need to be returned).
- Food should be fully cooked.
- Each item should include a description of the meal, or ingredients of a dish, along with heating instructions, if necessary.

Getting Help with Other Needs

Use a checklist to figure out the major areas where you'll need help. Add others as necessary. If reviewing this list only makes you feel overwhelmed, start small. Pick just one task to delegate. (*To help you get started, refer to the **Addendum: Checklist of tasks and needs** near the end of this document.*)

Who can help?

Your neighbors, family members, friends, members of your faith community, high school students, and friends of friends are all potential helpers. Think in wide circles when you look for help.

"I've found out about a lot of resources from attending a support group. I look for information in the newspaper, from friends, and from just asking around. Our visiting nurse, for example, told us about some helpful services."

— Gail, caregiver of patient with myeloma

Create a list of potential helpers

Many people would like to help, but don't know how to offer help or what you really need. Take the first step by writing out a list of contacts who may want to help. (*To help you get started, check the **Addendum: Contact list template** at the end of this document.*)

Use this list of contacts to identify who has offered to help, and how they might like to help. You can also use this form to identify those you would like to ask, or to clarify who you do or don't want to perform certain tasks (e.g., a friend who is great with your kids, but can't help with transportation).

Thanking your community

When ongoing help is no longer needed, consider sending a thank-you to members of your caring community. You may want to thank some special people with a small gift, but many people may prefer a loving note or card.

If your community is large, consider sending an e-card. Here are some Web sites that you can use to send a free thank-you note in electronic form.

- www.123greetings.com/thank_you
- www.bluemountain.com/category.pd?path=82931
- www.gratefulness.org/ecards

Web Resources for Creating a Care Plan

www.caregiverhelper.com: Lets you start a Web page to build a master care plan. Family and friends who want to help can add themselves to volunteer for a task.

www.lotsahelpinghands.org: Helps you alert your family and friends to your needs and enables them to schedule times when they can help.

www.caringbridge.org: Enables you to create a secure Web page to send health updates, write journal entries, and display photographs. Visitors can keep up to date on a patient's condition and write messages of support.

www.caremanager.org: Offers listings of geriatric care managers who can help coordinate and/or oversee the care of older adults.

Addendum: Checklist of tasks and needs

Do you have friends or family members who are wondering how to help? Consider the checklists below to see if there are areas where others might be of assistance.

Transportation

- Accompany patient to hospital or clinic during a treatment day.
- Drive patient to other appointments.
- Transportation for family members (e.g., children to school, older persons to the store).

Household duties

- Prepare and deliver a meal.
- Shop for groceries.
- Care for the yard, rake leaves, or shovel snow.
- Pick up and sort mail.
- Small handyman tasks (e.g., fixing a clogged drain, putting in storm windows)
- Shop for holidays; wrap holiday gifts.
- Take care of pets; walk the dog.
- Take care of plants.
- Do laundry.
- Clean the house.

Child care

- Take children on a play date or special outing.
- Stay at the house with the kids while parents are at the hospital or clinic.
- Bring children to the hospital for visits.
- Help children or siblings with homework assignments.
- Take kids to sports practice, games, or other activities.

Elder care

- Provide transportation for appointments or errands.
- Spend time with an older person in his or her home.

Patient support

- Help schedule visits (when the patient requests).
- Spend time with the patient so the primary caregiver can go out (for exercise, to a movie, to get a haircut, etc.).
- Serve as a contact person to keep others updated. (If it's OK with the patient, add a coordinator's phone number to the patient's voicemail so that the coordinator can receive calls inquiring about the patient's treatment.)

Additional needs

- Serve as coordinator, guiding those people who want to help (this often means maintaining a calendar showing needed helper tasks, along with who is responsible).
- Regularly update a Web page for the family and/or patient.
- Send out informational e-mails or help create an e-mail list.
- Find information for the patient or caregiver (e.g., a Web search or literature search).
- Ask a computer-savvy person to help connect with others via the Web, such as setting up a Web page or an e-mail distribution list (group e-mail).

Addendum: Contact list template

Name: _____
Address: _____
Home Phone: _____
Cell Phone: _____
E-mail: _____
General Availability: _____
Notes:

Name: _____
Address: _____
Home Phone: _____
Cell Phone: _____
E-mail: _____
General Availability: _____
Notes:

Name: _____
Address: _____
Home Phone: _____
Cell Phone: _____
E-mail: _____
General Availability: _____
Notes:

Name: _____
Address: _____
Home Phone: _____
Cell Phone: _____
E-mail: _____
General Availability: _____
Notes: