A Guide for Caregivers

This information will help you care for someone who has cancer.

Being a caregiver can be an extremely rewarding experience, but at the same time, a stressful and difficult one. Caregivers are often balancing work and family demands, along with emotional, physical, financial, and spiritual distress, as they help people cope with a life-threatening illness.

We hope the information in this guide will help make your role as a caregiver a positive experience—both for you and the person you’re caring for. We’ve addressed some of the issues that are important to caregivers. Your issues may be different, but we hope we’ve given you ideas to help you address some of your concerns. If you ever feel like you need more guidance, please speak with the patient’s doctor, nurse, or social worker. We’re here to help and support you through this process.

At Memorial Sloan Kettering (MSK), the Caregivers Clinic provides support specifically for caregivers who are having difficulty coping with the demands of being a caregiver. For more information, please call Dr. Allison Applebaum’s office at 646-888-0200 or go to www.mskcc.org/cancer-care/doctor/allison-applebaum.

Communicating With the Doctor

It’s important that you and the patient understand the planned treatment and its possible side effects. Some people don’t feel comfortable talking with a doctor. They may be afraid of asking a silly question. They may be worried that they won’t understand what the doctor is saying. Below are some suggestions to help you prepare.

Tips

- If possible, one person should go with the patient to all appointments. This
person should also be the key contact who shares information about the patient to family members and friends. If questions come up, this person can be the one to call the doctor. The patient should tell their doctor to communicate with this person.

- Before each appointment, write down key concerns and a list of questions. Speak with other family members so you also know what they’re worried about. Here are some questions you may want to ask:
  
  - What type of cancer does the patient have?
  - What is the stage of the cancer?
  - Is there any evidence that the cancer has spread?
  - What is the recommended treatment and why? Are there other treatment options?
  - How often will treatment be given and how long will it last?
  - What are the side effects of the treatment? How can they be managed?
  - When should I contact the doctor or nurse? How do I contact them?

- At the beginning of the appointment, tell the doctor that you have questions to ask. This helps the doctor set aside time to answer your questions. Try to ask your most important questions first.

- Write down the doctor’s answers. If you don’t understand something, ask the doctor to explain it or to draw a picture, if you think that will help. Keep your notes in a folder with other medical information you have gathered.

- If there’s something you still don’t understand when you get home, call the doctor’s office. The nurse who works with the doctor may also be able to answer many of your questions.

- Interpreter services are available at all times for any patients whose primary language isn’t English. These services are available either in person or by telephone. It’s best to make arrangements for an interpreter before the appointment. Please let your doctor or nurse know if this is necessary.
For more information on communicating with doctors, read the following resources:

Caregiver Action Network
caregiveraction.org/_doc/pdf/DrCaregvr.pdf

National Coalition for Cancer Survivorship (NCCS)
www.canceradvocacy.org/resources/publications/teamwork.pdf

Caring for the Patient

In your role as caregiver, you may have to learn:

- New skills to take care of the patient.
- How to give medications.
- How to give emotional support.

Providing physical care and managing symptoms

As a caregiver, you may need to provide physical care to the patient or supervise other people who are doing it. You may also need to:

- Manage symptoms, such as pain or nausea.
- Change dressings or handle medical equipment.
- Help with bathing or going to the bathroom.

Taking on these new tasks can feel like a burden. At times, it may feel difficult for both you and the patient. It’s normal to feel this way. With time, most caregivers feel that they can learn these skills.

Tips

- Make a list of what needs to be done each day to help you better organize your time. Include the patient in planning and decision-making as much as possible.
- Encourage the patient to do as much of their own care as possible.
• Ask family and friends for help with caring for the patient. See the section “Getting Family and Friends Involved in Care” for guidance.

• Put medical supplies and equipment you may need in one place.

• Make the home setting safe. Here are some ideas:
  o Arrange the furniture so there’s enough space to walk.
  o Secure loose rugs to the floor with rug pads to prevent tripping.
  o Put handrails and grab bars next to the toilet and inside the tub or shower.
  o Place nonslip surfaces on the tub or shower floor.
  o Provide a stool so the patient can sit while showering.
  o Use a wheelchair with lift-off arms to transfer the patient more easily.
  o Install an elevated toilet to make it easier for the patient to sit down and stand up.

• Know what side effects the treatment may cause. Ask the doctor or nurse what symptoms the patient may have and how to manage them. Know when you should call the doctor’s office.

• Tell the doctor or nurse if you have any concerns about providing care. If you don’t know how to do something the patient will need, ask them to tell you or show you what to do. Ask for written information that you can use as a guide.

• Know who to call for medical problems or concerns. Keep important phone numbers with you and near the phone at home.

• If you don’t think you can manage the patient’s care at home, ask the case manager about a home health care agency. A home health care agency can provide the following based on medical eligibility and insurance coverage:
  o Visits from a home health aide for a few hours a week
  o Visits from a nurse
  o Help getting medical supplies and equipment
  o Set up physical therapy
Managing medications

People with cancer may need to take several different medications at once. Some may be for treating the cancer, while others may help treat side effects or other health problems. You may need to help the patient take medications or be sure they're taken on time.

Tips

- Keep a list of everything the patient is taking. Include medications that don't need a prescription, such as vitamins, herbs, and supplements. Carry this list with you. To download and print a useful medication management list, go to www.nextstepincare.org/uploads/File/Guides/Medication/Medication_Management_Guide/Medication_Management.pdf

- Know the name of each medication, the dosage, why it's prescribed, and when it should be taken. For more information about prescription and over-the-counter medications, go to the MedlinePlus website at: www.nlm.nih.gov/medlineplus/druginformation.html

- Keep all handouts the pharmacist gives you in a folder. Also keep any inserts that come with the medication. These explain how the medication should be given and possible side effects. Ask the doctor or nurse how these side effects should be managed, if they happen.

- Use a calendar to record each medication and the time of day it should be taken.

- Use a pill container with compartments to store medications. These are helpful to remember when to take a medication and to see if it has been taken. Use a pill splitter if you have to cut tablets in half. For liquid medications, use a measuring spoon or dropper.

- Check the medication supply once a week to make sure you have at least a week's supply on hand. This will give you time to refill the prescription or get a new one if you need to. Some medications, such as those to manage pain, cannot be refilled without a new prescription, and only a small amount can be called into the pharmacy by phone.

- Each time you see the doctor, bring a list of any medications that will run out soon. If the medication will run out before the doctor's appointment, call the office to ask for a new prescription.
- Give medications exactly as the doctor or nurse told you. Have the patient take all prescribed doses, even if they're feeling better.

- When the patient leaves home for any length of time, even just for a few hours, they should take that day’s medications with them. A delay in travel plans could result in a late or missed medication, which could harm the patient.

- If the patient is having an unwanted side effect, tell the doctor. They may be able to change the dose or give a different medication.

- Keep a list of all the medications the patient is allergic to. Also note anything else the patient is allergic to, such as foods. Ask the patient about wearing a MedicAlert® bracelet or necklace. Healthcare providers will check it if the patient can’t talk and will know not to give certain medications. For more information about getting a MedicAlert® bracelet or necklace, go to www.medicalert.org

- Get to know your local pharmacist and use them as a resource. You can also look for a 24-hour pharmacy in your area that delivers medication.

For more information on managing medications, read the following resources:

Agency for Healthcare Research and Quality (AHRQ)
*Your Medicine: Be Smart. Be Safe*
http://www.ahrq.gov/sites/default/files/publications/files/yourmeds_0.pdf

Next Step in Care
*Medication Management: A Family Caregiver's Guide*

Visiting Nurse Service of New York
*5 Tips for Managing Medications*
www.vnsny.org/home-health-care-and-you/caregiver-resources/-tips-to-manage-medications

**Providing emotional support**

Patients have many feelings during their cancer experience, ranging from acceptance to sadness, fear, anger, anxiety, and depression. Some patients may
have times of wonder and doubt, or they may question their religious beliefs. Their feelings may be a reaction to the cancer or side effects, a fear of being alone, a loss of independence, or thoughts about end of life. These are common responses to dealing with illness.

You may need to help the patient find ways to cope with the emotional and spiritual side of cancer. This can be hard. Also, patients may direct their feelings, including their anger about being sick, toward the caregiver. This may be hurtful to you, but it may help if you know that this isn’t unusual.

Remember, you don’t have to manage on your own. There are many resources available for caregivers. You, too, may experience feelings of distress, isolation, anger, and fear. See the section “Taking Care of Yourself” for information on getting the emotional support you need.

Tips

- Try to keep daily life as normal as possible. At the end of each day, reflect on how things went and identify positive experiences.
- Plan fun activities. Consider things you and the patient enjoy doing together. You could listen to music together, watch TV or a movie, or if the patient is physically able, go shopping. If the patient is feeling up to it, make dates for family and friends to visit.
- Encourage the patient to be as active as possible. Exercise may provide an emotional boost.
- Encourage the patient to discuss their concerns openly. Ask the patient not “how” but “what” they’re feeling. Listen without trying to make everything better. Let the patient know that it’s okay to feel sad and frustrated at times.
- There may be times when the patient doesn’t want to talk about having cancer. Respect the patient’s decision not to discuss all aspects of the illness with you.
- Ask the patient about getting counseling.
  - The MSK Counseling Center provides counseling for individuals, couples, families, and groups, as well as medications to help with anxiety and depression. For more information, or to make an appointment, call 646-888-0100.
• The MSK Department of Social Work also provides counseling to the patient, caregivers, and their families. For more information, call 212-639-7020.

• Ask the patient about joining an in-person or virtual (online) support group. For more information, please call the MSK Department of Social Work at 212-639-7020.

• The MSK Resources for Life After Cancer (RLAC) Program provides education, support, and advocacy services for patients who have finished treatment. For more information, call 646-888-8106 or go to www.mskcc.org/cancer-care/survivorship/services-survivors

• Talk about your own feelings. Be honest. Share your concern about the uncertainty of the future, and emphasize that you’re a team: “We’re in this together.”

• Being together may be the most important thing you can offer. Hugging, touching, and holding hands can be very comforting.

• Ask the patient about things they have used to cope at difficult times in the past. Prayer, meditation, humor, or relaxation techniques may all be helpful at times.

• Ask the patient if they want to speak with someone who provides spiritual support.

• Anxiety and depression are common among cancer patients. Learn to recognize the symptoms.
  
  • Anxiety may appear as angry outbursts, irritability, uncontrollable worry, or difficulty concentrating or sleeping. The patient may have racing thoughts; feel nervous, shaky, or jittery; feel a lump in their throat or tightness in their chest or stomach; be short of breath; or feel that their heart is racing.

  • Depression may appear as sadness or anger. Some patients withdraw, lose interest, or stop enjoying things they usually like. They can have a hard time making decisions. They may feel tired, not be able to concentrate or sleep well, not feel like eating, or feel hopeless.

• Call the doctor or nurse if the anxiety or depression last more than 2 weeks. If they cause the patient a lot of distress, call sooner. Medication and
counseling can improve some of these symptoms and the patient’s quality of life. Ask the doctor or nurse if the patient should see a specialist.

**Preparing for Hospital Admission**

When patients with cancer are admitted to the hospital, new issues may come up. The following information will help you prepare for this.

**Medical issues**

Ask the patient’s doctor or nurse what to expect before, during, and after the patient’s hospitalization, including:

- Are any medical tests needed before admission? Does the patient need to change their diet or medication schedule to prepare for these tests?
- How long will the patient be in the hospital?
- What will the patient’s condition be when they’re discharged?
- Will there be any restrictions on physical activity? Will the patient need to stay in bed?
- Will it be safe for the patient to be home alone?

**Insurance issues**

If you know beforehand that the patient will be admitted, contact the patient’s insurance company and ask:

- Has the patient been preauthorized for the surgery, procedure, or treatment?
- What is and isn’t covered under the insurance plan?
- What will the patient have to pay out-of-pocket?
- Is home care covered? What kinds of home medical equipment are covered?

You may also want to check with the human resources department at the patient’s place of work.

Not all home care services are covered by insurance. The patient’s case manager can tell you what’s covered. This is based on the insurance and what the doctor prescribes. You can pay for care that you or others can’t give and isn’t covered
by insurance. Agencies can send housekeepers, aides, or private duty nurses. The case manager can give you names of home care agencies in your area. When you call them, ask about fees.

Some patients need rehabilitation to get stronger after leaving the hospital. The case manager can give you the names and numbers of places covered by the patient’s insurance. You can visit them to see which one you think is best for the patient. The case manager will give the insurance company and other healthcare providers the information they need.

If you have any questions or concerns about insurance issues, talk with the case manager or contact Patient Billing at 646-227-3378.

Preparing for Hospital Discharge

You can plan ahead to get ready for the patient to come home. Here are some suggestions:

- Purchase any over-the-counter medications that the patient will need when they come home, such as laxatives, stool softeners, supplements, or pain medications.
- Stock up on easy-to-prepare foods and take-out menus.
- Organize the items that the patient will use every day so you can find them easily.
- Set aside clothing for the patient that is loose, comfortable, and easy to put on and take off.
- Be sure the patient has shoes with nonslip soles that can be easily put on and taken off.
- Contact family and friends to see who can help after the patient comes home. Make a schedule and sign people up to take the patient to appointments, do housekeeping, shopping, and cooking, and visit with the patient. See the section “Getting Family and Friends Involved in Care” for tips on how to do this.
- If the patient lives alone or in a home with stairs, it may be easier for them to stay with family or friends while recovering.
• Some religious communities have people who help other members in need. Ask the patient if they belong to such a community.

Transportation

Getting to and from medical appointments can take time and cost a lot of money. If the patient lives in New York City and is physically able, you may consider taking the bus or subway. There are kneeling buses that lower the front entrance of the bus to make it easier for passengers to get on and off. These buses also have lifts for people in wheelchairs.

Access-a-Ride is a shared-ride, door-to-door service for people with disabilities who live in New York City. It’s run by the New York City Metropolitan Transit Authority (MTA). The service is for people who are unable to use a public bus or subway for some or all of their trips. A one-way fare is the same as a subway or bus ride, which is currently $2.75. The service operates 24 hours a day, 7 days a week. You must register to get the service. For more information, go to web.mta.info/nyct/paratran/guide.htm or call 877-337-2017.

Tips

• Get the patient’s treatment schedule from the doctor or nurse as soon as they know it. This will let you plan ahead.

• Ask family and friends if they can take the patient to some of their appointments.

• Ask the social worker or case manager to help you find resources in your community to help with transportation.

• Some organizations that provide transportation require patients to share rides. Check with them to see how early you need to be ready and where you should wait.

• Taxis and limousines may make it more convenient to travel, but they’re more costly.

• CancerCare is an organization that has funds available to help patients in need with getting to and from their appointments. For more information, go to www.cancercare.org/financial

• The American Cancer Society has a program called Road to Recovery that
provides transportation to and from treatment for people with cancer who don’t have a ride or aren’t able to drive themselves. For more information, go to www.cancer.org/treatment/supportprogramsservices/road-to-recovery

- Medicaid may provide transportation based your Medicaid coverage and if your meet medical eligibility.

- Some transportation programs require you to apply. Do it early—the process can take up to a few months.

- If you’re using a public or private service for transportation, have a backup plan. The service may not be available when you need it.

- MSK has several free patient shuttles for patients and their caregivers. These shuttles travel between Memorial Hospital (1275 York Avenue) and other MSK locations in Manhattan. For more information, including shuttle types and times, go to www.mskcc.org/locations/visiting-us/patient-shuttle.

- Travel directions and parking information for all MSK locations are available on the MSK website at www.mskcc.org/locations/visiting-us/directions-parking

- If you need to stay near the hospital, MSK has a list of accommodations online at www.mskcc.org/locations/visiting-us/accommodations

- For a list of other organizations that can help with transportation, please see the “Resources” section.

Financial Issues

Managing the finances associated with the patient’s care can be difficult. Your social worker or case manager can give you information about community resources. Medical costs that insurance companies don’t cover are often tax-deductible. These costs include:

- Mileage for car trips to a doctor or clinic.
- Treatment costs not covered by insurance.
- Prescription medications.
- Medical equipment.
- The cost of some meals.
Ask your accountant about what costs are tax-deductible.

**Health insurance and medical bills**

Review a copy of the patient’s health insurance policy. Make a list of what is and what isn’t covered. If you have questions, contact the insurance company. You can also contact Patient Billing at 646-227-3378.

If you have questions about MSK medical bills, contact the Patient Accounts Department at 646-227-3228.

**Tips**

- Maintain the patient’s current medical insurance plan. Don’t let it expire. Make sure that the premiums are paid on time. It may be difficult to get new coverage. Patients who lose or leave their jobs may be eligible for Consolidated Omnibus Budget Reconciliation Act (COBRA). This program allows you to keep the insurance for a limited time, if the full premium is paid.

- Preauthorization is required for some medical procedures, surgeries, and treatments. Ask the insurance company whether you need to get it or whether the healthcare provider will do it. Submit claims for all expenses as soon as you can. Keep records of bills that are paid and those that are not.

- If the patient’s policy won’t cover a procedure or treatment, ask how you can file an appeal with your insurance company. This may help the patient get it covered.

- Some insurance companies assign a case manager to patients with cancer. The case manager works with the patient and the hospital. If you feel this would be helpful, ask the insurance company if a case manager can be assigned to the patient.

- For more information on getting help with insurance issues, see the “Resources” section.
Cost of medications

Prescription medications can be very expensive. Some may not be covered by the patient’s health insurance plan.

Tips

- Find out whether the patient’s insurance has a prescription medication plan.
- If a medication isn’t covered, ask the patient’s doctor if a less expensive medication is available.
- Some pharmaceutical companies have programs that provide free or low-cost prescription medications to those in need.
- Shop around. Medications bought through a mail-order pharmacy or online often cost less than those at local drug stores.
- Be careful about buying medications outside of the United States. Standards for making medications may be lower.
- Save receipts for all medications. These costs may be tax-deductible.
- There are many organizations that can help patients with the cost of medications. See the “Resources” section for more information.

Out-of-pocket expenses

Families and caregivers often have out-of-pocket expenses (costs that aren’t covered by insurance plans). There are resources available to help with some of these costs. Some costs also may be tax-deductible.

Tips

- Speak with the social worker to see what help is available to cover out-of-pocket expenses. Most programs require you to enroll. Apply as soon as you can, since the process often takes some time.
- Check with the patient’s church, synagogue, mosque, or other place of worship to see if they provide financial aid.
- Many mortgage and utility companies will work with you at a time of serious illness. Sometimes, they will lower payments.
- Get receipts for all costs of care and treatment. Call the patient’s local
Internal Revenue Service (IRS) office or accountant to see what costs can be deducted.

- Talk with family and friends about helping out with finances. Allow them to help, if they’re able.
- For a list of resources that can help cover out-of-pocket expenses, see the “Resources” section.

Legal Issues

You may need to help the patient with their legal affairs. Although this may be hard to bring up, talking about it early can help you protect the patient’s interests. You may need to help the patient with an advance directive or a will. You should also be aware of the Patients’ Bill of Rights. It’s posted throughout MSK and online at: www.mskcc.org/cancer-care/hospital-information/patients-rights

Advance directives

Advance directives allow patients to say what kind of care they would want if they become very sick or as they near the end of their life. Each state has its own laws related to advance directives. However, most states recognize a healthcare agent, a living will, or both.

Healthcare agent

A healthcare agent (also called a proxy or representative) is a person that the patient chooses to make healthcare decisions for them if they can’t do it themselves. They’re involved in medical decisions only and don’t have legal authority to make decisions about the patient’s finances or anything else.

Once the patient has chosen a healthcare agent and the person has agreed, it needs to be put in writing by completing a healthcare proxy form. Forms are available from your healthcare provider at MSK, a Patient Representative, or on the website listed below.

In New York State, a Health Care Proxy form becomes valid once it’s signed and dated in front of 2 witnesses. Anyone who is 18 years of age or older can be a witness; however, the healthcare proxy cannot be the witness. The witnesses will also need to sign the form. A lawyer or a notary isn’t needed to complete this
form. Give a copy of the completed healthcare proxy form to all of the patient’s healthcare providers, the healthcare agent, and their lawyer, if they have one. The patient should also keep a copy of the form in a safe place.

If you live in New York, more information is available at www.health.ny.gov/professionals/patients/health_care_proxy/

If you live in New Jersey, more information is available at www.nj.gov/health/advancedirective/ad/forums-faqs/

To download health care proxy forms from any state, go to Caring Connections at www.caringinfo.org

Living will
A living will is a document that states the patient’s wishes about their medical care. It goes into effect if they become unable to make decisions for themselves. In the document, the patient specifies which treatments they do or don’t want to receive if they’re in this situation. For more information on living wills, go to www.caringinfo.org

Tips

- Talk to the patient about advance directives. Ask about their wishes for medical treatment. Help the patient complete the legal forms.

- Know who the healthcare agent is. If you’re the healthcare agent, make sure you’re willing to do this. It may be your job to make sure the patient’s wishes are followed.

- Make sure the healthcare agent has a copy of your advance directive(s). To be safe, have the patient appoint someone else to be a back-up healthcare agent. Give copies of the advance directive to family members and the patient’s lawyer.

- If you’re the healthcare agent, make sure the doctors and nurses know the patient’s wishes. If you feel that the patient’s wishes aren’t being followed, call Patient Representatives at 212-639-7202.

- If you have questions about advance directives, contact a patient representative at the number above.
Will

A will is a legal document that outlines who gets money, property, and other assets when a person dies. It can also be used to name the legal guardians of children under the age of 18. Having a will helps to prevent disputes over the patient’s possessions after their death. Without a will, a court will step in to distribute a person’s assets.

Each state has its own requirements for wills, so it’s best to have a lawyer write the will. They can make sure that the will follows state laws.

Tips

• If the patient doesn’t have a lawyer, ask family and friends for names of lawyers. You can also call your state or local bar association. They may provide a list of names.

• Make sure the patient reviews the will to make sure that it says what they want.

• Know where the patient keeps the original will. Keep a copy in a safe place.

Health Insurance Portability and Accountability Act (HIPAA)

HIPAA is a law that protects the privacy of patients’ medical records and other health-related information. All MSK patients receive a notice of our privacy practices.

Tips

• Under HIPAA, healthcare providers can only talk about the patient’s medical condition with family and friends who are involved in the patient’s care and only if the patient doesn’t object.

• If the healthcare team members don’t know that you’re involved in the patient’s care, the only way they can talk to you about the patient is if the patient has given them permission to do so.

• If you have any questions about HIPAA, contact the MSK Privacy Office at 646-227-2056. For more information about privacy practices at MSK, call the Privacy Office or go to www.mskcc.org/about/policies-standards/privacy
Family and Medical Leave Act (FMLA)

There may be times during a patient’s illness when you feel torn. You have to work, but you’re also caring for the patient. Some caregivers find it helpful to take a leave of absence from work during this time. The FMLA requires most employers to give you up to 12 weeks of unpaid leave for certain health or family reasons. Caring for a family member who is ill may be one of those reasons. Ask your employer if you’re eligible for the FMLA.

Tips

- Ask your human resources or benefits department about your company’s FMLA policy. Ask them to tell you what your rights are and what you must do during your leave of absence. File all of the paperwork on time.
- You may need to provide your employer with medical proof that you need to take a leave of absence. A letter from the patient’s doctor should be enough.
- If you don’t qualify for the FMLA, ask your employer whether you can take a leave of absence anyway. Make sure to confirm that you will have a job when you return. Ask if it will be the same job. If not, ask how it may be different.

For more information about the FMLA, go to the US Department of Labor website at www.dol.gov/whd/fmla

Getting Family and Friends Involved in Care

Often, it isn’t possible for one person to manage all of the patient’s needs. You may need to have others help you.

Family and friends may want to help, but may not know how. Or, they may not offer to help in ways that you expect. Although some people may disappoint you, others may give you a lot of support. Allowing family members and friends to take part in the patient’s care gives them a chance to feel the rewards of caregiving. The following tips will help you organize family and friends who are willing to take part in the patient’s care.
Tips

- Identify tasks that you need help with and note them on a calendar.
- Ask family and friends when they’re available and what jobs they feel most comfortable doing. Or, contact each person with a specific request. Be as clear as you can so your expectations are understood. Give a time frame in which you need to hear back about whether or not they can do the task. Some examples of requests include:
  - Driving the patient to and from a chemotherapy appointment that is expected to last 4 hours
  - Cooking dinner 1 day a week
  - Meeting the children at the school bus on days of treatment
  - Doing the laundry once a week
  - Visiting the patient at lunch time while you’re at work
- As you hear back from each individual, note their responses on the calendar to make sure everything is taken care of. Planning ahead will help prevent a crisis.

Taking Care of Yourself

As a caregiver, you may be juggling many duties. In addition to caring for the patient, you may have a job. You may have household chores, like grocery shopping, cooking, and cleaning. You may have children or others you need to care for. And most importantly, you have yourself to take care of. Balancing these tasks while making sure you have enough time to attend to your own needs can be very challenging.

Caregivers often feel guilty or selfish about taking time for themselves. Some are afraid that something will happen to the patient if they aren’t there. However, if you’re going to remain in the caregiver role for more than a short time, you must take care of yourself. If you don’t, you will soon feel “burned out” and will not able to do the important work of caregiving.
Tips

- Make your own health a priority. Keep all of your doctor’s and dental appointments, get enough rest, eat properly, and exercise regularly. Walking is a great way to get started.
- Try to get enough sleep each night.
- Take time for leisure activities. Plan to do things for yourself that you enjoy.
- Keep up your physical appearance. Get your hair cut, have a manicure or pedicure, and wear clothes you feel good in. Sometimes, just taking the time to attend to your physical appearance can help you feel better emotionally.
- Speak with family members and friends who are willing to help with household chores.
- If you feel that changes to your work schedule would be helpful, speak with your supervisor. Refer to the information about the FMLA.
- Respite programs provide breaks for caregivers for a limited time. Ask your social worker for more information.
- Ask yourself how you’re feeling. Some caregivers find it helpful to keep a journal, others find it helpful to speak out loud about their thoughts and feelings, and some prefer to express themselves through art or dance.
- Think about individual counseling or joining a support group for caregivers. At MSK, the Caregivers Clinic provides support specifically for caregivers of patients with any site or stage of cancer who are having difficulty coping with the demands of being a caregiver. For more information, please call Dr. Allison Applebaum at 646-888-0020 or go to www.mskcc.org/cancer-care/doctor/allison-applebaum
- Virtual twice-monthly groups are also available for caregivers of adult MSK patients in active treatment. For more information or to register, email virtualprograms@mskcc.org or go to www.mskcc.org/vp
  - A group on Mindfulness Medication meets on the first Tuesday and third Thursday of every month.
  - A support group for caregivers meets on the second Thursday and fourth Wednesday for every month.
- The MSK blog, “OnCancer,” has helpful information on caregiving. You can
find the blog at www.mskcc.org/blog/caring-caregivers

- The Resources for Life After Cancer Treatment (RLAC) Program has support programs for caregivers and patients. For more information, call 646-888-8106 or go to www.mskcc.org/experience/living-beyond-cancer/services-survivors

- Respect your own religious needs. Continue your practices as often as you can.

- Recognize signs of caregiver “burnout.” You may feel tired, angry, or depressed. You may have trouble sleeping or feel anxious. If any of these signs or symptoms last more than 2 weeks, consider talking to someone. Social workers, psychologists, psychiatrists, and clergy can all be helpful.

- Your workplace may have an employee assistance program. The type of help varies but often includes counseling for financial problems, stress, and depression.

- The MSK Integrative Medicine Service provides patients and caregivers with services such as massages, acupuncture, yoga classes, reflexology, meditation, and nutritional consults. For more information, call 646-888-0800 or go to www.mskcc.org/cancer-care/integrative-medicine.

- The American Cancer Society, the National Alliance for Caregiving, and the Caregiver Action Network all have tips on taking care of yourself and preventing burnout. See the “Resources” section for more information.

**Benefits of Caregiving**

Despite the demands of caring for a patient with cancer, the role of caregiver can be an incredibly satisfying and rewarding one. Many caregivers report positive experiences from caregiving, such as:

- Increased meaning and purpose in one’s life
- Personal growth
- Greater capacity for acceptance and empathy
- A sense of giving back to someone else
- Increased confidence
• The satisfaction of knowing that a loved one is getting excellent care
• Improved relationships
• Family closeness
• Greater appreciation for life
• Shift in priorities and values
• Increased spiritual well-being

As you move forward, don’t forget to tell yourself how special you are.

Resources

Many of the resources listed in this guide can be found on the Internet. If you don’t have a computer or if you don’t know how to use the Internet, check with your local public library or community center.

Information and support for caregivers

American Cancer Society
www.cancer.org
800-227-2345
Provides information and support to patients with cancer and their caregivers. Publications that may be helpful include American Cancer Society Complete Guide to Family Caregiving, Cancer Caregiving A-to-Z, and When the Focus Is on Care.

CancerCare
www.cancercare.org
800-813-HOPE (800-813-4673)
National nonprofit organization that helps people with cancer and their caregivers through counseling, education, information, referrals, and direct financial assistance.

Cancer Support Community
www.cancersupportcommunity.org
Provides support and education to people affected by cancer.
Caregiver Action Network
www.caregiveraction.org
202-772-5050
Provides education and support for those who care for loved ones with a chronic illness or disability.

Caring Bridge
www.caringbridge.org
Social networking space where you can connect with other caregivers, share news, and receive support.

Family Caregiver Alliance (National Center on Caregiving)
www.caregiver.org
Develops services and publications based on caregiver needs and offers programs at local, state, and national levels.

Gilda’s Club
www.gildasclubnyc.org
A place where men, women, and children living with cancer find social and emotional support through networking, workshops, lectures, and social activities.

LGBT Cancer Project
lgbtcancer.com
Provides support and advocacy for the LGBT community, including a online support groups and a database of LGBT-friendly clinical trials.

National Cancer Institute’s Cancer Information Service
www.cancer.gov
800-4-CANCER (800-422-6237)
Provides education and support to cancer patients and their families. Publications (available online and in print) that may be helpful include:

Caring for the Caregiver: Support for Cancer Caregivers
pubs.cancer.gov/ncipl/detail.aspx?prodid=P102

When Someone You Love Is Being Treated for Cancer: Support for Caregivers
pubs.cancer.gov/ncipl/detail.aspx?prodid=P225
When Someone You Love Has Advanced Cancer: Support for Caregivers

Next Step in Care
www.nextstepincare.org
Provides guides and checklists for family caregivers and healthcare providers working together toward improved transitions in care.

Books

100 Questions and Answers About Caring for Family or Friends With Cancer
Authors: Susannah L. Rose, MSSW and Richard T. Hara, PhD
Publisher: Jones and Bartlett Publisher (2005)

Always on Call: When Illness Turns Families into Caregivers
Editor: Carol Levine
Publisher: United Hospital Fund of NY (2004)

Caregiving: A Step-by-Step Resource for Caring for the Person with Cancer at Home
Authors: Peter S. Houts and Julia A. Bucher
Publisher: American Cancer Society (2000)

Caregiver’s Guide for Bone Marrow/Stem Cell Transplant
Author: National Bone Marrow Transplant Link (nbmtLINK)
nbmtlink.org/documents/cg2.pdf

The Human Side of Cancer: Living with Hope, Coping with Uncertainty
Authors: Jimmie C. Holland and Sheldon Lewis
Publisher: Quill (2001)

Love, Honor & Value: A Family Caregiver Speaks Out about the Choices & Challenges of Caregiving
Author: Suzanne Mintz, President and Cofounder of the National Family Caregivers Association
Publisher: Capital Books (2002)

Share the Care: How to Organize a Group to Care for Someone Who is Seriously Ill
Authors: Sheila Warnock and Cappy Capossela
Publisher: Simon & Schuster (2004)
www.sharethecare.org
Home care services

Visiting Nurse Associations of America
www.vnaa.org
888-866-8773
Provides an online database to help you locate a Visiting Nurse Association close to the patient.

Visiting Nurse Service of New York
www.vnsny.org
800-675-0391 (Available 24 hours a day, 7 days a week)
Provides a full range of home care services in New York, including home health aides and escorts to go with patients to appointments or to pick them up.

Transportation and travel

Access-a-Ride
web.mta.info/nyct/paratran/guide.htm
877-337-2017
Shared-ride, door-to-door service for people with disabilities who live in New York City.

Air Charity Network
www.aircharitynetwork.org
877-621-7177
Provides travel to treatment centers.

Corporate Angel Network
www.corpangelnetwork.org
866-328-1313
Arranges free travel to cancer treatment centers across the country using empty seats on corporate jets.

Joe’s House
www.joeshouse.org
877-563-7468
Provides a list of places to stay near treatment centers for people with cancer and their families.
National Patient Travel Center
www.patienttravel.org
800-296-1217 (Helpline is available 24 hours a day, 7 days a week)
Helps arrange air transportation for patients.

Health insurance issues

AARP
www.aarp.org/health/insurance
888-687-2277
Provides information that can help people 50 years of age and older understand health insurance choices.

Health Insurance Information, Counseling, and Assistance Program (HIICAP)
www.aging.ny.gov/healthbenefits
800-342-9871
Program run by the New York State Office for the Aging that provides free health insurance information and helps with Medicare, Medicaid, HMOs, Medigap insurance, medical bills, and long-term care insurance.

Patient Advocate Foundation
www.patientadvocate.org
800-532-5274
Provides patients with arbitration, mediation, and negotiation to settle issues with access to care, medical debt, and job retention related to their illness.

Cost of medications

AARP Prescription Discount Program
www.aarppharmacy.com
877-422-7718
Program that was created to provide exclusive discounts on FDA-approved prescription medications and specialty medications at participating retail network pharmacies and through Walgreens Mail Service.

Center for Drug Evaluation and Research
www.fda.gov/Drugs/ResourcesForYou/Consumers/default.htm
Government agency that provides information for consumers and answers to frequently asked questions about generic drugs.
Good Days
www.mygooddays.org
877-968-7233
Offers financial assistance to pay for copayments during treatment. Patients must have medical insurance, meet the income criteria, and be prescribed medication that is part of the Good Days formulary.

Healthwell Foundation
www.healthwellfoundation.org
800-675-8416
Provides financial assistance to cover copayments, health care premiums, and deductibles for certain medications and therapies.

NeedyMeds
www.needymeds.com
800-503-6897
Provides information about programs that can help patients who can’t afford their medications.

NYRx
www.nyrxplan.com
Provides prescription benefits to eligible employees and retirees of public sector employers in New York State.

Partnership for Prescription Assistance
www.pparx.org/en
888-4PPA-NOW (888-477-2669)
Helps qualifying patients without prescription medication coverage get free or low-cost medications.

Patient Access Network Foundation
www.panfoundation.org
866-316-7263
Provides assistance with copayments for patients with insurance.
Patient Advocate Foundation  
www.patientadvocate.org  
800-532-5274  
Provides access to care, financial assistance, insurance assistance, job retention assistance, and access to the national under insured resource directory.

RxHope  
www.rxhope.com  
877-267-0517  
Provides assistance to help people obtain medications that they have trouble affording.

State-sponsored prescription plans  
Contact the program directly for eligibility and applications.

New York:  
Elderly Pharmaceutical Insurance Coverage (EPIC) Program  
www.health.state.ny.us/health_care/epic/  
800-332-3742

New Jersey:  
Pharmacy Assistance to the Aged and Disabled Program (PAAD)  
www.state.nj.us/humanservices/doas/services/paad  
800-792-9745  
For a list of programs in other states, call (800) 813-HOPE or go to  
www.cancercare.org

Together Rx Access  
www.togetherrxaccess.com  
800-444-4106  
Offers discounts on prescription medications to Medicare enrollees who don’t have prescription medication coverage.

US Food and Drug Administration  
www.fda.gov/ForConsumers/ProtectYourself/default.htm  
Has information about buying medications and medical supplies online.
Out-of-pocket expenses

God’s Love We Deliver
www.glwd.org
212-294-8102
Prepares and delivers meals to people who are ill and are unable to prepare meals themselves. Available in New York City and Hudson County, New Jersey.

Healthcare Hospitality Network
www.nahhh.org
800-542-9730
Provides information about free or low-cost temporary housing to patients who are receiving treatment away from home and their families.

Meals on Wheels Association of America
www.mowaa.org
888-998-6325
Provides home-delivered meals to people in need. The website lists programs by city and state.

Ronald McDonald House New York
www.rmh-newyork.org
212-639-0100
Coordinates services and provides support for parents who have children with cancer.

US Internal Review Service (IRS)
www.irs.gov
800-829-1040
Provides information about which medical expenses are tax deductible.

Legal issues

AARP
www.aarp.org (search “Advance Directives”)
888-687-2277
Provides members and their spouses with tips, legal seminars, and low, fixed rates for preparing wills.
American Bar Association
www.abanet.org
800-285-2221
Provides information on legal services, local bar association referrals, and educational publications.

Caring Connections
www.caringinfo.org
800-658-8898
Provides information and support on advance directives, caring for a loved one, living with an illness, or grieving a loss. State-specific advance directives are available for download.

National Cancer Legal Services Network
www.nclsn.org
Free cancer legal advocacy program.

If you have any questions or concerns, talk with a member of your healthcare team. You can reach them Monday through Friday from 9:00 AM to 5:00 PM at ____________________. After 5:00 PM, during the weekend, and on holidays, please call____________________. If there’s no number listed, or you’re not sure, call 212-639-2000.

A Guide for Caregivers

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