PATIENT & CAREGIVER EDUCATION

A Guide for Caregivers

This guide will help you care for someone with cancer.

Being a caregiver can be a very rewarding experience, but at the same time, can be very challenging. Caregivers often need to balance their work and family life, along with emotional, physical, financial, and spiritual distress as they help people cope with a life-threatening illness.

The information in this guide can help make your role as a caregiver a positive experience for both you and the person you're caring for. In this guide, we discuss some of the issues that are important to caregivers. Your issues may be different, but we hope to give you ideas to help with some of your concerns.

If you ever feel like you need more help, talk with the patient's doctor, nurse, or social worker, or reach out to MSK's Caregivers Clinic. The Caregivers Clinic provides support for caregivers coping with the demands of being a caregiver. To learn more, visit www.msk.org/caregivers, call 646-888-0200, or read *Caregiver Support Services* (www.mskcc.org/pe/caregiver-services).

Benefits of caregiving

Even though being a caregiver can be demanding, it can also be very rewarding.

Many caregivers have positive experiences from caregiving, including:

- Increased meaning and purpose in their life.
- Personal growth and increased confidence.
- Increased ability to be more empathetic and accepting.
- A sense of giving back to someone else.
- The pride in knowing that a loved one is getting very good care.
- Improved relationships, and feeling closer to family.
- Greater appreciation for life.
- Change in their priorities and values.
- Improved spiritual health.

As you move forward with caregiving, don't forget to tell yourself how special you are.

Talking with healthcare providers

It's important that you and the patient understand the planned cancer treatment and its possible side effects. It's important to talk with the patient's healthcare providers and ask questions to help you understand.

Not everyone feels comfortable talking with a healthcare provider and asking questions. Patients and caregivers may be afraid of asking a silly question. They may be worried that they won't understand what the healthcare provider is saying. The following tips can help you get ready to talk with the patient's healthcare provider.

Tips for talking with healthcare providers

- If possible, a primary caregiver should go with the patient to all their appointments. This person should also be the main contact who shares information about the patient with family members and friends. If concerns or questions come up at home, this person can be the one to call the doctor. The patient should tell their healthcare provider to communicate with this person.
- Before each appointment, write down yours and the patient's main concerns and a list of questions. Talk with other family members so you also know what they're worried about and what questions they have. Bring this list to the appointment. Here are some questions you may want to ask:
    - What type of cancer does the patient have?
    - What stage is the cancer?
    - Is there any evidence that the cancer has spread?
    - What is the recommended treatment? Why? Are there other treatment options?
    - How often will the patient get treatment? How long will it last?
    - What are the side effects of the treatment? How can we manage them?
    - How might this treatment affect the patient's mood and behavior?
    - 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 these notes in a special folder with all the patient's other medical information.
    - 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 and caregivers whose first language isn't English. The interpreter can talk with you either in person or by telephone. It's best to arrange for an interpreter before the appointment. Tell your doctor's office if this is needed. Visit www.msk.org/experience/become-patient/international-patients/private-translation-services to learn more about language assistance services at MSK.

Communication resources

To learn more about communicating with healthcare providers, 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 need to learn some new skills and terms. These can include:

- Information about the patient's disease and its treatment.
- How to manage medical equipment.
- How to give medications to the patient.
- How to provide emotional support for the patient.

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, such as a home health aide.

You may also need to help the patient:

- Manage their symptoms, such as pain or nausea (feeling like they might throw up).
- Change their bandages or handle their medical equipment.
- Perform daily activities, such as bathing, getting dressed, or going to the bathroom.

Taking on these new tasks can be hard at times. It can feel unfamiliar 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 for caring for the patient

- Make a list of what needs to be done each day to help you organize your time. Include the patient in the planning and decision-making as much as possible.
- Encourage the patient to be as independent as possible.
- Ask other family and friends for help with caring for the patient. Read the section "Getting Family and Friends Involved in Care" for help with this.
- Put all the medical supplies and equipment you may need in one place so you can get to them easily.
- Ask the patient's healthcare provider what side effects of their treatment are and how to manage them. Also, ask when you should call the doctor's office.
- Tell the patient's healthcare provider 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 or show you what to do. Ask for written information that you can use as a guide.
- Know who you can call for medical problems or concerns. Keep important phone numbers with you at all times and near the phone at home.

- If you don't think you can manage all of the patient's care at their home, ask the patient's healthcare provider about a home healthcare agency. A home healthcare agency can provide visits from healthcare professionals to the patient's home to help with their care. The services they can provide depend on the patient's insurance coverage and what skilled nursing needs they may have. A home health agency can provide services such as:
  - Visits from a nurse.
  - Visits from a home health aide for a few hours per week. The number of hours depends on the patient's skilled nursing needs.
  - Help with getting medical supplies and equipment for the patient.
  - Physical therapy.

Tips for making the home safe

The following are ways you can help make the patient's home safe.

- Move the furniture around to make sure there is enough space for the patient to walk or get around in their wheelchair.
- Put rug pads under loose rugs to keep them from moving to prevent tripping.
- Put handrails and grab bars next to the toilet, and inside the tub or shower.
- Put nonslip surfaces or mats on the tub or shower floor.
- Get a shower seat so the patient can sit while showering.
- Use a wheelchair with lift-off arms to move the patient from the wheelchair to the couch or bed.
- Install a raised toilet seat to make it easier for the patient to sit down and stand up while going to the bathroom.

To learn more about durable medical equipment for the home, read the following resources:

- *About Durable Medical Equipment: Bed Canes* (www.mskcc.org/pe/bed-canes)
- *About Durable Medical Equipment: Shower and Bathtub Accessories* (www.mskcc.org/pe/shower-bathtub-accessories)
- *About Durable Medical Equipment: Transport Wheelchairs* (www.mskcc.org/pe/transport-wheelchairs)
- *About Durable Medical Equipment: Toilet Accessories* (www.mskcc.org/pe/toilet-accessories)

Managing medications

People with cancer may need to take many different medications at once. Some may be for treating the cancer, and others may help treat side effects or other health problems. You may need to help the patient take their medications or make sure they take them on time.

Tips for managing medications

- Keep a list of every medication the patient is taking. Include medications that don't need a prescription, such as over-the-counter medications, vitamins, herbs, and supplements. Carry this list with you and bring it to all their medical appointments.
    - Visit www.nextstepincare.org/Caregiver_Home/Medication_Management_Form to download and print a useful medication management list.
    - Be sure you know the name of each medication, the dosage, why it's prescribed, and when it should be taken. To learn more about prescription and over-the-counter medications, visit www.msk.org/pe and search for the patient's medication name. You can also visit www.aboutherbs.com to read more about herbs and supplements.

- Keep all handouts the pharmacist gives you in a folder. Also, keep any papers or instructions that come with the medication. These explain how the medication should be given and its possible side effects. Ask the patient's healthcare provider how these side effects should be managed if they happen.
- Use a calendar or calendar reminders to note the time of day each medication should be taken.
- Use a pillbox to store medications. These can help patients remember when to take their medication and to see if it has been taken.
- Use a pill splitter to cut tablets in half, if needed. For liquid medications, use a measuring spoon or dropper.
- Check the patient's supply of medication once a week to make sure you have at least 1 week's supply available. This will give you time to refill the prescription or get a new one if needed. Some medications, such as those to manage pain, can't be refilled without a new prescription, and can only be refilled if a certain amount of time has passed.
- Every time you see the patient's doctor, bring a list of all the medications that will run out soon. If the medication is going to run out before the doctor's appointment, call the office to ask for a new prescription.
- Give medications to the patient exactly as the healthcare provider told you to. Make sure the patient takes all prescribed doses of the medication, even if they're feeling better.
- When the patient leaves home for any amount of time, even just for a few hours, they should take that day's medications with them. A delay in their travel plans might make them take their medication late or miss their dose, and this can be harmful.
- If the patient has any medication side effects, tell their healthcare provider. They might be able to change the dose or give them a different medication.
- Keep a list of all medications the patient is allergic to. Also note anything else the patient is allergic to, such as foods.

- Ask the patient to wear a MedicAlert® bracelet or necklace. Healthcare providers will check it if the patient can't talk and will know not to give certain medications. Visit www.medicalert.org to learn more about getting a MedicAlert bracelet or necklace.

- Become familiar with your local pharmacist for more help. You can also look for a 24-hour pharmacy in your area that delivers medication.

Medication resources

To learn more about managing medications, read the following resources:

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

Next Step in Care
Medication Management: A Family Caregiver's Guide
www.nextstepincare.org/Caregiver_Home/Medication_Management_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. They may feel:

- Sad
- Angry
- Scared
- Anxious
- Depressed

Some patients may struggle with making sense of their cancer diagnosis, or they may question their religious or spiritual beliefs.

Their feelings may be because of the cancer or treatment side effects, fear of being alone, loss of independence, or thoughts about the end of life. These are normal responses when coping with an illness.

You may need to help the patient find ways to discuss their emotional distress and talk openly about their fears or worries. This can be hard. Also, patients may direct their feelings, such as their anger about being sick, toward their caregiver. This may be upsetting to you, but it may help if you know that this is normal.

You may also have feelings of stress, loneliness, anger, and fear. But you don't have to manage these feelings on your own. There are many resources available for caregivers. Read the section "Taking Care of Yourself" for information on getting the emotional support you need.

Anxiety and depression

Anxiety and depression are common in people with cancer. You should learn the symptoms of these conditions and how you can help.

Anxiety is a strong feeling of worry or fear. Feelings of anxiety can range from mild uneasiness to overwhelming panic. There are many signs of anxiety, such as nervousness, angry outbursts, and trouble sleeping. To learn more about anxiety, read *Managing Anxiety* (www.mskcc.org/pe/anxiety).

Depression is a strong feeling of sadness. A person with depression may seem angry, sad, tired, or lose interest in things they usually like. To learn more about depression, read *Managing Depression During Cancer Treatment* (www.mskcc.org/pe/depression-cancer-treatment).

Call the patient's healthcare provider if they show any symptoms of anxiety or depression that last more than 2 weeks. If these conditions cause your loved one a lot of distress, call their healthcare provider sooner. Medication and counseling can improve some of these symptoms and the patient's quality of life. Ask the patient's healthcare provider if the patient should see a specialist, such as a social worker, psychologist, or psychiatrist.

Tips for providing emotional support:

- Try to maintain daily routines for both you and the patient and try to keep daily life as normal as possible. At the end of each day, think about how things went and what positive experiences you had.
- Plan fun activities. Think about 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 feels up to it, make dates for family and friends to visit.
- Encourage the patient to be as active as possible. Exercise can provide an emotional boost.
- Encourage the patient to talk about their concerns openly. Ask them about their emotions. Try asking not "how" but "what" they're feeling. Listen to them without trying to make everything better. Let them know that it's OK to feel sad and angry at times.
- Sometimes, the patient might not want to talk about having cancer. Respect their decision not to discuss all parts of their illness with you.
- Individual counseling can also be very helpful for patients. It can provide a safe space for patients to discuss their fears or worries that they might feel uncomfortable talking to their families about. To learn more about support available through MSK's Counseling Center and MSK's Department of Social Work, read the "Resources" section of this guide.
- Ask the patient if they would be interested in joining an in-person or virtual (online) support group. Visit www.msk.org/vp to learn more about virtual programs.
- Talk about your own feelings and be honest. Share your concerns about the future if you have them, 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 with hard times in the past. Praying, meditating, using humor, or relaxing can all be helpful at times.

- Ask the patient if they'd like to speak with someone who provides spiritual support, such as a chaplain.

Getting ready for hospital admission

Sometimes, patients with cancer are admitted to the hospital. If this happens, new issues may come up. The following information will help you get ready for a patient's hospital stay.

Medical issues

Ask the patient's doctor or nurse what to expect before, during, and after the patient's hospitalization. You can ask questions such as:

- 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 need help with after they're discharged? Will they need any special equipment?
- Will there be any limits on their physical activity after they leave the hospital? Will the patient need to stay in bed?
- Will it be safe for the patient to be home alone after they leave the hospital?

Insurance issues

If you know beforehand that the patient will be admitted to the hospital, you should contact their insurance company. You should ask the insurance company questions about the patient's coverage, such as:

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

Home care

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 patient's insurance and what the doctor prescribes for them. The patient may need more care than you can give them after leaving the hospital. If their insurance plan doesn't cover this care, you can pay for it out-of-pocket (you will pay for the care yourself). Read the "Out-of-pocket costs" section to learn more.

Home care agencies can send private home health aides, or private duty nurses to help care for the patient. The case manager can give you names of home care agencies in your area. When you call them, it's important to ask about their fees for services.

Rehabilitation therapy

Some patients need rehabilitation therapy to get stronger after leaving the hospital. Rehabilitation therapy can help patients regain their strength and adjust to physical changes that may impact their daily life. This can involve working with a physical or occupational therapist who are professionals trained in helping people move and function better. If a patient is able to go home after they're discharged, they may be referred to a certified home health agency for rehabilitation therapy. Services such as a visiting nurse, physical and occupational therapy would be provided in the patient's home for a period of time.

Sometimes patients may need to temporarily live in a skilled nursing facility after they're discharged from the hospital. This will allow them to get rehabilitation therapy services every day. You can visit these facilities to see which one you think is best for the patient. You can also visit www.medicare.gov to compare local facilities and review their ratings. The nurse case manager at the hospital will provide the insurance company and other healthcare providers the information they need to see if a patient qualifies for services at a certain facility.

If you have any questions or concerns about insurance issues, talk with the case manager, or contact Patient Billing at 646-227-3378. There are also Patient Financial Services Representatives assigned to each site at MSK who can help you if you have any insurance issues. Contact the Patient Financial Services at 212-639-3810 or ask your healthcare provider who the representative is for your

treatment site.

Preparing for hospital discharge

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

- Buy any over-the-counter medications that the patient will need when they come home (such as laxatives, stool softeners, supplements, or pain medications) before they leave the hospital.
- Stock up on foods that you can easily make 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's loose, comfortable, and easy to put on and take off.
- Make sure the patient has shoes with nonslip soles that can be easily put on and taken off. Read *How To Choose Safe Shoes to Prevent Falling* (www.mskcc.org/pe/safe-shoes) to learn more.
- Talk with family and friends to see who can help after the patient comes home. Make a schedule and ask people to sign up to take the patient to appointments, clean around the house, shop, cook, and visit with them. Read the section "Getting Family and Friends Involved in Care" for tips on how to do this.
- If the patient lives alone, it may be easier for them to stay with family or friends while they recover, if possible.
- Some religious communities have people who help other members in need. Ask the patient if they belong to a community like this.
- Read *Planning for Your Discharge* (www.mskcc.org/pe/planning-discharge) to learn more about helping the patient get ready to leave the hospital.

Transportation

Getting to and from medical appointments can take time and cost money. If the patient lives in New York City and is physically able, you could take the bus or subway. There are kneeling buses that lower the front entrance of the bus to make it easier for people to get on and off the bus. 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 can't use a public bus or subway for some or all of their trips. It costs the same as a subway or bus ride. The service operates 7 days a week. There is an application process that must be completed, and a patient must be certain criteria in order to qualify for services. To learn more, go to web.mta.info/nyct/paratran/guide.htm or call 877-337-2017.

Transportation tips

- Ask the patient's healthcare provider for the patient's treatment schedule as soon as they know it. This will help you plan ahead for travelling to and from appointments.
- Ask other family and friends if they can take them to some of their appointments.
- Ask the patient's social worker or case manager to help you find resources in your community to help with transportation.
- Some organizations that provide transportation will make people 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 easier to travel, but they can cost more money.
- Medicaid may provide transportation based on the patient's Medicaid coverage and if the patient meets the medical eligibility.
- You may need to apply for some transportation programs, such as Access-a-Ride, Para-Transit, Access Link NJ Transit, or volunteer ride services. Make sure you apply early because the process can take up to a few months.

- If you're using a public or private service for transportation, especially the subway or bus, have a backup plan. The service may not be available when you need it.
- MSK has many free patient shuttles (also called the jitney) for patients and their caregivers. These shuttles travel between Memorial Hospital (1275 York Ave.) and other MSK locations in Manhattan. Visit www.msk.org/locations/visiting-us/patient-shuttle for more information, including shuttle types and times.
- Visit www.msk.org/parking for travel directions and parking information for all MSK locations.
- If you need to stay near the hospital, visit www.mskcc.org/locations/visiting-us/accommodations for a list of places to stay.

For a list of other organizations that can help with transportation, read the "Transportation and travel" part of the "Resources" section.

Financial issues

It can be hard to manage the financial parts of cancer care. Your social worker or case manager can give you information about community resources that can help. Medical costs that insurance companies don't cover are often tax-deductible. This means that claiming them on your tax return can help you pay fewer taxes. These costs include:

- Mileage (how far you drove) for car trips to a doctor or clinic.
- Treatment costs that aren't covered by insurance.
- Prescription medications.
- Medical equipment.

You can talk to an accountant about which costs are tax-deductible.

Health insurance and medical bills

You should review the patient's health insurance policy. Make a list of what's covered by the plan and what isn't. If you have questions about the patient's insurance policy, contact their insurance company. You can also contact Patient Billing at 646-227-3378 for help.

Health insurance can be confusing. You can visit www.msk.org/insurance-assistance/insurance-information/terms for a helpful glossary of insurance terms. For questions about MSK medical bills, contact the Patient Accounts Department at 646-227-3228.

Financial and insurance tips

- Make sure you keep the patient's medical insurance plan current. Don't let the plan expire. Make sure that the premiums (monthly fees you pay for the insurance) are paid on time. This is important because it may be hard for the patient to get new insurance coverage if their current plan expires.
- People who lose their healthcare coverage may be able to be part of a program called Consolidated Omnibus Budget Reconciliation Act (COBRA). This program lets you keep your insurance for a short time if the premium is paid in full. Visit www.dol.gov/general/topic/health-plans/cobra to learn more about COBRA.
- Preauthorization is required for some medical procedures, surgeries, and treatments. Ask the patient's insurance company if you need to get preauthorization or if the healthcare provider will do it for you. You should submit medical claims (special medical forms for insurance providers) for all expenses as soon as you can. It's important to keep good records of bills that are paid and those that aren't.
- If the patient's insurance policy doesn't cover a procedure or treatment, ask the insurance company how you can file an appeal. This may help the patient get it covered.
- Some insurance companies assign a case manager to people 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.

- To learn more about getting help with insurance issues, read the “Resources” section.

Cost of medications

Prescription medications can be very expensive. The patient’s health insurance plan not cover some medications.

Tips for managing medication costs

- Find out if the patient’s insurance has a prescription medication plan.
- If a medication isn’t covered, ask the patient’s doctor if a cheaper medication is available.
- Some pharmaceutical companies have programs that provide free or low-cost prescription medications to people in need.
- If some medications are costly, try shopping around for cheaper options. Some medications might be cheaper if you buy them through a mail-order pharmacy or online.
- Be careful if you decide to buy medications outside of the United States. This is because the rules set for making medications may be lower than those in the United States.
- Save the receipts from all medications. Medication costs may be tax-deductible.
- There are many organizations that can help patients pay for their medications. Read the “Resources” section to learn more.

Out-of-pocket costs

Patients 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 of these costs also may be tax-deductible.

Tips for out-of-pocket costs

- Speak with the social worker to see what help is available to cover out-of-pocket expenses. You may need to apply for some programs. Apply for these programs as soon as you can since the process can take some time.
- Check with the patient's church, synagogue, mosque, or another place of worship to see if they can provide financial help.
- Many mortgage and utility companies will work with you during a time of serious illness. Sometimes, they will lower your payments.
- Get receipts for all costs of care and treatment and save them. Call the patient's local Internal Revenue Service (IRS) office or accountant to see what costs can be deducted in their taxes.
- Talk with other family and friends about helping financially. Let them help, if they're able to.
- For a list of resources that can help cover out-of-pocket expenses, read the "Resources" section.

Advance care planning

You may need to help the patient with their legal affairs, such as writing a will. This process is called advance care planning. This may be hard to talk about, but talking about it early on can help you protect the patient's interests and make sure they get the care they want. You may need to help the patient with an advance directive or a will.

You should also read the Patients' Bill of Rights. It's posted online at www.msk.org/cancer-care/hospital-information/patients-rights and throughout MSK patient care facilities.

Read *Advance Care Planning for People With Cancer and Their Loved Ones* (www.mskcc.org/pe/advance-care-planning) for more detailed information about this process.

Advance directives

Advance directives are written instructions on how the patient wants medical decisions to be made if they're not able to communicate or make the decisions themselves. The 2 most common types of advance directives are a healthcare proxy and a living will. Each state has its own laws related to advance directives. However, most states recognize a healthcare proxy, a living will, or both.

Healthcare agent

A healthcare agent (also called a proxy or representative) is the 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 the legal authority to make decisions about the patient's finances or anything else. To learn more, read *How To Be a Health Care Agent* (www.mskcc.org/pe/health-care-agent).

Once the patient has chosen a healthcare agent, and the person has agreed, it needs to be put into writing. The patient can do this by completing a healthcare proxy form. Forms are available from your healthcare provider at MSK, a Patient Representative, or on the following websites:

- If you live in New York, visit www.health.ny.gov/professionals/patients/health_care_proxy to learn more.
- If you live in New Jersey, visit www.nj.gov/health/advancedirective/ad/forums-faqs to learn more.
- Visit Caring Connections at www.caringinfo.org to download healthcare proxy forms from any state.

In New York State, a Healthcare Proxy form becomes official once it's signed and dated in front of 2 people that serve as witnesses. Anyone who is 18 years old or older can be a witness, but the healthcare agent can't be the witness. The witnesses will also need to sign the proxy form.

You don't need a lawyer or notary (licensed person who witnesses the signing of important documents) to complete the form. Once the form is signed, make copies of it. Give a copy of the completed form to all the patient's healthcare providers, their healthcare agent, and their lawyer, if they have one. The patient

should also keep a copy of the form in a safe place.

Living will

A living will is a document that states the patient's wishes about their medical care. It will go into effect if the patient becomes unable to make decisions for themselves. In the document, the patient states which treatments they do or don't want. Visit www.caringinfo.org for more information on living wills.

Advance care planning tips

- Talk to the patient early on about advance directives. Ask them about what kind of medical treatments they would want and what treatments they wouldn't want. Help them complete the legal forms.
- Know who the patient's healthcare agent is. If you're the healthcare agent, make sure you're willing to do this. It's the healthcare agent's job to make sure the patient's wishes are followed. To be safe, ask the patient to have an alternate healthcare agent in case the primary agent is unable to carry out the patient's wishes. The alternate agent should also be identified and documented in the healthcare proxy form.
- Make sure the healthcare agent has a copy of the patient's advance directive(s). Give copies of the advance directive to other family members and the patient's lawyer, if they have one.
- If you're the healthcare agent, make sure all healthcare providers know the patient's wishes. If you feel like they aren't following the patient's wishes, call Patient Representatives at 212-639-7202.
- If you have questions about advance directives, contact a Patient Representative at 212-639-7202.

Will

A will is a legal document that plans out who gets money, property, and other assets (things a person owns) when a person dies. It can also be used to decide who the legal guardians of children under the age of 18 will be, if needed. Having a will helps to prevent arguments about what the patient would like to give away to different people if they die. Without a will, a court will step in to give away a person's assets to others.

Tips for writing a will

Each state has its own rules for writing wills, so it's best to have a lawyer write the will. They can make sure that the will follows state laws. If the patient can't afford a lawyer, there are pro-bono law services available in many places which may be able to provide legal help at low or no cost.

- If the patient doesn't have a lawyer, ask family and friends for names of lawyers they recommend. You can also call your state or local bar association. They may be able to provide a list of lawyers that can help.
- Make sure the patient reads their will to make sure it says exactly what they want.
- It's important to know where the patient keeps the original copy of their will. Make copies of it and keep them 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 get a notice of MSK's privacy practices. They describe how medical information may be used and shared and how to get access to this information.

Understanding HIPAA

- 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 says it's OK.
- 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's health care is if the patient gives them permission to.
- If you have any questions about HIPAA, contact the MSK Privacy Office at 646-227-2056. To learn more about privacy practices at MSK, visit www.msk.org/about/policies-standards/privacy or call the Privacy Office.
- Visit the Office for Civil Rights website at www.hhs.gov/hipaa/index.html to learn more about HIPAA.

Family and Medical Leave Act (FMLA)

If you're working and also taking care of someone with cancer, there may be times when you feel like there's too much to do. Some caregivers find it helpful to take some time off from work during this time. The FMLA law makes most employers give you up to 12 weeks of unpaid leave for some health or family reasons. Caring for a family member who's sick may be one of those reasons. Ask your employer if you're eligible for leave through the FMLA.

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 before your time away from work. Be sure to file all of the paperwork on time.
- You may need to show your employer medical proof that you need to take time off. If needed, ask the patient's doctor for a letter for this.
- If you don't qualify for the FMLA, ask your employer if you can take some time off anyway. It's important to know if you will have a job when you return or if you will have a different job. Talk about these details with your employer.

Visit the US Department of Labor website at www.dol.gov/whd/fmla to learn more about the FMLA.

Getting family and friends involved in care

It's usually not possible for 1 person to manage all of the patient's needs. You may need to ask others to help you.

Family and friends may want to help but might not know how. It's important to tell family and friends what your needs are so they can help in the way you need them to. Then, they can provide the most support to you and the patient. Letting family members and friends take part in the patient's care gives them a chance to feel the rewards of caregiving too. The following tips will help you organize family and friends who are ready to take part in the patient's care.

Tips for getting others involved

- Find tasks that you need help with and write them on a calendar or make a list.
- Ask family and friends when they're available and what tasks they feel most comfortable doing. You can also ask each person to do a specific task. Be very clear about what's needed so that everyone understands. Ask people to respond by a certain date if they can do a task.
- Some examples of tasks you can ask others to do include:
    - Taking the patient to and from a chemotherapy appointment, which may take a long period of time.
    - Cooking dinner for the patient 1 day a week.
    - Meeting the patient's children at the school bus on days when the patient has treatment.
    - Doing the laundry once a week.
    - Visiting the patient at lunchtime while you're at work.
- As you hear back from each person, write down their responses on the calendar or list to make sure everything is taken care of. Planning ahead will help you keep from forgetting anything.

Taking care of yourself

As a caregiver, you may be handling a lot of important tasks. In addition to caring for the patient, you may have a job. You may have household chores to do for yourself, 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 all these tasks while making sure you have enough time to focus on your needs can be very hard.

Caregivers often feel guilty or selfish for taking time for themselves. Some are afraid that something will happen to the patient if they aren't there. But, if you need to be a caregiver for a long period of time, you have to take care of yourself. If you don't, you will soon feel like you're too stressed or tired to do anything and won't be able to do the important work of caregiving.

Tips for taking care of yourself

- Make sure you keep up with your own health care. Keep all of your doctor's and dentist appointments, get enough rest, eat properly, and exercise regularly. Walking is a great way to start exercising.
- Try to get enough sleep every night.
- Plan time to do activities you enjoy.
- Take care of yourself physically. Get your hair cut, have a manicure or pedicure, and wear clothes you feel good in. Sometimes, just taking the time to help yourself look the way you want to can help you feel better emotionally.
- Ask family members and friends to help you with household chores.
- If you feel that changes to your work schedule would be helpful, talk with your supervisor. Refer to the information about the FMLA in the 'Family and Medical Leave Act' section.
- Ask yourself how you're feeling and consider your own emotions. Some caregivers find it helpful to keep a journal. Others find it helpful to speak out loud about their thoughts and feelings. Others may prefer to express themselves through art, yoga, or dance.
- Consider going to individual counseling or joining a support group for caregivers. Call the MSK caregivers clinic if you're interested in joining a group or starting counseling. To learn more about counseling, visit www.msk.org/counseling. To learn more about joining a support group, visit www.msk.org/experience/patient-support/counseling/social-work-support/social-work-support-groups.

- Virtual (online) support groups are also available for caregivers of people undergoing treatment at MSK. Visit www.msk.org/vp to learn more.
    - Our virtual group called The Three R's of Self- Care: Rest, Relaxation, Rejuvenation offers caregivers a brief introduction in mindfulness meditation. You will learn how to take time to rest the mind, relax the body, and feel ready to resume caregiving responsibilities with more clarity and energy.
        - This group meets on the first Tuesday of each month from 2 to 2:30 p.m. and the third Thursday of each month from 11 to 11:30 a.m.
    - Our virtual support group for caregivers offers the opportunity to discuss the stresses, challenges, and rewards of providing care for someone with cancer.
        - This group meets on the second Tuesday of each month from 5:30 to 6:30 p.m. and the fourth Wednesday of each month from 1 to 2 p.m.
    - You can register for a virtual program directly on the group's page on www.msk.org/vp
    - An Inpatient Caregiver Support Group also meets monthly in-person. To learn more and to register, email forcaregivers@mskcc.org.
- The MSK blog, "OnCancer," has helpful information on caregiving. You can find the blog at www.msk.org/blog/caring-caregivers.
- The Resources for Life After Cancer Treatment (RLAC) Program has support programs for caregivers and patients. To learn more, visit www.msk.org/experience/living-beyond-cancer/services-survivors or call 646-888-8106.
- If you're religious, continue to practice your beliefs and traditions as often as you can.
- Learn the 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 can be different depending on where you work, but often includes counseling for financial problems, stress, and depression.
- The MSK Integrative Medicine and Wellness Service provides patients and caregivers with services such as massages, acupuncture, yoga classes, reflexology, meditation, and nutritional consults. These are all fee for service, and you'll need to pay for them out-of-pocket. To learn more, visit www.msk.org/integrativemedicine or call 646-449-1010.
- 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 to learn more.

Resources

Many of the resources listed in this guide can be found online. 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.

MSK support services

Counseling Center
www.msk.org/counseling
646-888-0200
Many people find that counseling helps them. We provide counseling for individuals, couples, families, and groups, as well as medications to help if you feel anxious or depressed. To make an appointment, ask your healthcare provider for a referral or call the number above.

Resources for Life After Cancer (RLAC) Program
www.msk.org/experience/living-beyond-cancer/services-survivors
646-888-8106
At MSK, care doesn't end after active treatment. The RLAC Program is for patients and their families who have finished treatment. This program has many services, including seminars, workshops, support groups, counseling on life after treatment, and help with insurance and employment issues.

Social Work

www.msk.org/socialwork

212-639-7020

Social workers help patients, family, and friends deal with issues that are common for cancer patients. They provide individual counseling and support groups throughout the course of treatment and can help you communicate with children and other family members. Our social workers can also help refer you to community agencies and programs, as well as financial resources if you're eligible.

General support services

Talking With Children About Cancer

www.msk.org/experience/patient-support/counseling/kids-express

212-639-7029

This program provides information and support around how to talk to children about their parent's cancer diagnosis through individual consultations as well as adult and child support groups meetings.

American Cancer Society

www.cancer.org

800-227-2345

Provides information and support to patients with cancer and their caregivers. Books that may be helpful include *American Cancer Society Complete Guide to Family CaregivingCancer Caregiving A-to-Z*, and *When the Focus Is on Care*.

CancerCare

www.cancercare.org

800-813-HOPE (800-813-4673)

This is a national nonprofit organization that helps people with cancer and their caregivers through counseling, education, information, referrals, and financial assistance.

Cancer Support Community

www.cancersupportcommunity.org

Provides support and education for 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 create a website to connect with other caregivers, share news, and get support.

Family Caregiver Alliance (National Center on Caregiving)
www.caregiver.org
Offers services, education programs and publications for caregivers and offers programs at local, state, and national levels.

MJHS Health System's Resources for Caregivers
www.mjhs.org/resources-for-caregivers/
MJHS offers a library of helpful resources for caregivers.

Red Door Community
212-647-9700
www.reddoorcommunity.org
A place where people living with cancer find social and emotional support through networking, workshops, lectures, and social activities. Red Door Community used to be called Gilda's Club.

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

National Cancer Institute's (NCI) Cancer Information Service
www.cancer.gov
800-422-6237 (800-4-CANCER)
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
pubs.cancer.gov/ncipl/detail.aspx?prodid=P226

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

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 who can go with patients to appointments or 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.

CancerCare
www.cancercare.org
800-813-4673 (800-813-HOPE)
CancerCare has limited funds available to help patients that need help getting to and from their appointments. To learn more, go to www.cancercare.org/financial.

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.

Road to Recovery
www.cancer.org/treatment/supportprogramsservices/road-to-recovery
This is a program by the American Cancer Society that provides transportation to and from treatment for people with cancer who don't have a ride or can't drive themselves. To learn more and to find out if it's available in your county, visit their website.

Health insurance resources

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

This is a 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.

Medicare Rights Center

www.medicarerights.org

800-333-411

A nonprofit service organization that works to help older adults and people with disabilities get access to affordable healthcare. They provide education and counseling to help people understand their healthcare rights and benefits.

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 underinsured resource directory.

Medication assistance

AARP Prescription Discount Program

www.aarppharmacy.com

877-422-7718

This is a program that was created to provide AARP members 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 medications.

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's part of what Good Days will cover. Not all cancer types are covered, so it's important to check the website to see what is.

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

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 those that are retired after working in the public sector in New York State.

Partnership for Prescription Assistance
www.pparx.org/en
888-477-2669 (888-4PPA-NOW)
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
Their Co-Pay Relief Program can help with the cost of medications to those who financially qualify.

RxHope
www.rxhope.com
877-267-0517
Provides help for people to get medications that they can't afford.

State-sponsored prescription plans

You should contact the program directly to see if the patient qualifies and for program applications.

New York:
Elderly Pharmaceutical Insurance Coverage (EPIC) Program
www.health.state.ny.us/health_care/epic
800-332-3742
This program helps qualified older adults 65 and older pay for their prescription medications.

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, visit www.cancercare.org or call 800-813-4673 (800-813-HOPE).

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

US Food and Drug Administration
www.fda.gov/ForConsumers/ProtectYourself/default.htm
Has safety information for 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.hhnetwork.org
800-542-9730
Provides information about free or low-cost temporary housing to patients who are getting treatment away from home and their families.

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

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 Revenue 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.

Helpful 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
Link to guide: 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)

Things I Wish I'd Known: Cancer Caregiver Speak Out
Author: Deborah J. Cornwall
Publisher: Bardolf & Company

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

If you have questions or concerns, contact your healthcare provider. A member of your care team will answer Monday through Friday from 9 a.m. to 5 p.m. Outside those hours, you can leave a message or talk with another MSK provider. There is always a doctor or nurse on call. If you're not sure how to reach your healthcare provider, call 212-639-2000.

For more resources, visit www.mskcc.org/pe to search our virtual library.

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