

# Caregiver Handbook







## **Introduction**

If you're helping a family member or friend through cancer treatment, you are a **caregiver**. As a caregiver, you are an important part of the cancer care team. Some of your duties may include:

- Administering medications
- Keep track of appointments
- Managing side effects and reporting problems
- Keeping other family members and friends informed of what's happening

Your job is to be present, ask questions and take notes during doctor visits, learn who the members of the cancer care team are, and know how to contact them. Getting the right support and information can help both you and your loved one.

Being a caregiver can be challenging. The best thing you can do for yourself and your loved one is to stay organized and take time for yourself when you can. We hope this book helps you manage the days ahead.

**We would also like to invite you to attend our Caregiver Support Group:**

**March- June & September- December**

**1<sup>st</sup> Thursday of the month**

**1:00p.m. – 2:30p.m.**

**Location: 11 Day Power Play Resource Center**

**1<sup>st</sup> floor near the tower elevators**

**For more information, call 716-845-8051**



# 1. Tools to Stay Organized

## Communicating with Healthcare Team



Going to doctor visits during cancer treatment can be stressful and overwhelming for your loved one. If you are prepared for these visits and know the questions to ask, it will help you and your loved one manage the days to come.

Your loved one should tell their healthcare team that they can communicate directly with you. At registration, have your loved one sign the *Consent for Verbal Communication of Medical Information*. This will allow you to speak with members of the healthcare team.

Another way to be able to communicate with your loved one's healthcare team is to sign up on Roswell Park's Patient Portal, MyRoswell, as an authorized user:

- Go to <https://my.roswellpark.org>
- On the home page, click on the "Preferences" tab on the top navigation bar
- Go to "Authorized User" and ask patient to add your name and contact information

When accompanying your loved one to appointments, be prepared to take notes or ask if you can record the visit. Here are some questions to help you get started:

- What is the diagnosis/stage/grade of the cancer?
- What is the standard treatment for this diagnosis? Will it include surgery, chemotherapy, or radiation therapy?
- How long will treatment take?
- What are the risks and benefits of this treatment?
- How can we prepare for treatment?
- What are the side effects of these treatments? When and who should we call if the patient is ill?
- How will normal daily activities change during treatment such as work, childcare, exercise, hobbies?

## Medications

People with cancer may take many different medications. Some may be for treating the cancer, and others may help treat side effects or other health problems.



Here are some tips on how to best manage your loved one's medications during cancer treatment:

- Keep a list of every medication the patient is taking. Include medications that do not 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.
- Keep all the medications instructions and handouts from the doctor or pharmacist. These explain how the medication should be given and any possible side effects.
- Ask who and when you should call if your loved one experiences any side effects.
- Use a calendar to note the time of day each medication should be taken.
- Use a pillbox to store and sort medications.
- Check the patient's supply of medication once a week to make sure you have at least 1 week's supply available. 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.
- Use the following sheets to record all the medications and bring these to all appointments.





## **Calendars**

There are many ways to help keep track of appointments, including smart phones, pocket diaries, notebooks, journals, or wall calendars. Whichever method works for you, it is important to use it consistently. Record any appointments or events as soon as you know about them, and always check the calendar before you make plans.

You can also use a calendar to record any side effects or illnesses of your loved one so you can relay this information reliably to their healthcare team.

On the following pages are some sample calendars for you to use:











# WEEKLY PLANNER

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TUESDAY

MONDAY

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## 2. Medical Insurance, Finance, and Legal Issues



### Medical Insurance

It is important to make sure your loved one has up to date medical insurance before they begin their cancer treatment.

Many people are able to get health insurance through their employers. Some people may qualify for certain government-funded health care plans while others may be able to purchase insurance plans through the **Affordable Care Act (ACA)**, sometimes referred to as Obamacare. This health insurance includes coverage and protections for patients and their families. For more information, visit [healthcare.gov](https://healthcare.gov) or <https://nystateofhealth.ny.gov/>.

Whichever insurance your loved one has, it's important to be familiar with the services their plan covers and excludes. It's also helpful to review the list of services that may require pre-approval or prior authorization. Talk with Roswell Park's care team to help you if you have any questions or concerns.

Here are some additional tips to help you manage your loved one's medical insurance:

- Make sure the patient's medical insurance plan is current. Don't let the plan expire.
- If the patient does who lose their health insurance coverage from their job, they 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. For more information on COBRA, visit [www.dol.gov/general/topic/healthplans/cobra](https://www.dol.gov/general/topic/healthplans/cobra).
- Preauthorization may be required for some medical procedures, surgeries, and treatments. Ask the patient's insurance company if you need to get preauthorization or ask anyone in Roswell Park's care team to help you.
- 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.

## Financial Assistance

Roswell Park has a Financial Assistance Program for patients who may have difficulty paying for their medical care. For more information, call **716-845-4782**.

There are also many national cancer patient organizations who offer financial assistance to patients. For specific diagnoses, such as breast cancer, leukemia, or brain cancer, there may be specific organizations that can help. Visit The 11 Day Power Play Cancer Resource Center on the 1<sup>st</sup> floor of the hospital for more information.

For financial assistance for cancer patients, here are some organizations that can help:

**American Cancer Society** [www.cancer.org](http://www.cancer.org) Western NY Region Office, 101 John James Audubon Pkwy, Amherst NY 14228 **(716) 689-6981**

Offers referrals to patient navigators, social workers, and health insurance information specialists to help with issues facing cancer patients. They also help with transportation and lodging.

**Patient Advocate Foundation** [www.patientadvocate.org](http://www.patientadvocate.org) **800-532-5274**

The Patient Advocate Foundation provides “The National Financial Resources Guidebook for Patients”, a state-by-state directory of programs and services that assist patients with housing, utilities, food, and transportation to medical treatment. The Patient Advocate Foundation also helps insured patients who qualify to access co-pay assistance from pharmaceutical companies through its Co-Pay Relief Program. Learn more about the program at [www.copays.org](http://www.copays.org) or by calling (866) 512-3861.

**CancerCare:** [www.cancercare.org](http://www.cancercare.org) 800-813-HOPE

Provides over-the-phone assistance and referrals from licensed social workers who can help with insurance-related and financial issues, as well as payment assistance programs.

**Cancer Legal Resource Center:** [www.cancerlegalresourcecenter.org](http://www.cancerlegalresourcecenter.org)

Provides individuals with free information to answer any and all legal questions associated with their cancer care.

**Disability Rights Legal Center:** [www.disabilityrightslegalcenter.org](http://www.disabilityrightslegalcenter.org) 866-999-DRLC

Offers legal advocacy resources and over-the-phone support to patients and families needing assistance with health proxies or dealing with employment, consumer rights, insurance, or financial issues related to illness.

**National Coalition for Cancer Survivorship:** [www.canceradvocacy.org](http://www.canceradvocacy.org) 888-650-9127

Provides information on health insurance, employment, and financial assistance.

**The Assistance Fund,** [www.tafcares.org](http://www.tafcares.org) , **855-730-5871**

Helps patients facing high medical out-of-pocket costs by providing financial assistance for coinsurance, deductibles, and other health-related expenses. Visit [enroll.tafcares.org](http://enroll.tafcares.org) to apply.

**Cancer Care,** [www.cancercare.org/financial](http://www.cancercare.org/financial) **800-813-4673**

Offers limited financial assistance for cancer-related costs such as transportation and childcare, and our oncology social workers can help you find resources.

**Health Well Foundation [www.healthwellfoundation.org](http://www.healthwellfoundation.org) 800-675-8416**

Offers financial assistance for insurance copays, premiums, and deductibles as well as out of pocket expenses for supplies, supplements.

**Needy Meds [www.Needymeds.org](http://www.Needymeds.org) 800-503-6897**

Connects patients with organizations in their state that offer financial assistance for medication costs.

## **Roswell Park Social Work Department**

Our social workers are available to help with practical concerns, such as:

- transportation arrangements
- local lodging during treatment
- post-hospital care planning.
- advanced care planning and health care decision-making
- caregiver resources
- palliative care and hospice information and referrals

For more information, call our Social Workers at **716-845-8022**.

## **Legal Assistance**

As a result of your cancer diagnosis and treatment, you may need legal assistance with issues at your job or school, your treatment, your participation in a clinical trial not being covered by your insurance, or your loss of income and inability to pay your bills. Current patients and their families are eligible for one free, confidential legal consultation. Depending on the results, you may also qualify for free or discounted legal services. To make an appointment, call **716-845-1300 x6475** or email [LegalCare@RoswellPark.org](mailto:LegalCare@RoswellPark.org).

## **Health Care Decisions**

Preparing a few simple legal forms can help make sure that your loved one's wishes are followed, and the health care decisions stay in the hands of people they trust. These forms include **Health Care Proxy, Advanced Directive, and MOLST form**. If you have any questions or would like help in completing any of these forms, please contact the Social Work Department at **716-845-8022**.

## **Health Care Proxy**

A Health Care Proxy is a legal document that allows the patient to name someone as their "proxy" or "agent." In case your loved one is not able to make decisions or speak for themselves, the proxy is authorized to make the healthcare decisions. You or your loved one can request a Health Care Proxy form at Patient Access or in their clinic. You can also get the form online at NYS DOH's website:

<https://www.health.ny.gov/publications/1430.pdf>

## **Advanced Directive**

An **advance directive** is any written direction about the patient's health care treatment decisions and wishes while they still have the capacity to make such decisions.

## **MOLST Form**

The **MOLST** (medical orders for life sustaining treatment) form contains information regarding your loved one's health care decisions. It is offered to all Roswell Park patients and is recommended by the New York State Department of Health. The MOLST form is completed by the doctor with the patient and becomes part of their medical record.

For more information on the MOLST form, talk to your health care team or visit [www.health.ny.gov/professionals/patients/patient\\_rights/molst/](http://www.health.ny.gov/professionals/patients/patient_rights/molst/)

## **Difference between a Health Care Proxy, Advance Directive, and the MOLST form**

### **MOLST:**

- contains medical orders that reflect wishes about life sustaining treatments.
- applies immediately if the patient loses the ability to make health care decisions.
- is completed by a healthcare professional and the patient and then signed by a physician.
- is regularly reviewed and updated.

### **Advance Directive:**

- is the written documentation of health care treatment decisions?

### **Health Care Proxy:**

- is a type of advance directive that names another person to make health care decisions if the patient becomes incapable of making their wishes known.

## **Power of Attorney**

A power of attorney gives one or more persons the power to act on the patient's behalf as their agent. This power can be temporary or permanent. It can be limited to particular activities, such as financial, legal, and/or health decisions. It can also be general and all encompassing.

If you are interested, speak to an attorney or contact Roswell Park's Legal Assistance team at **716-845-1300 x6475** or email [LegalCare@RoswellPark.org](mailto:LegalCare@RoswellPark.org).

## Family Medical Leave Act

The Family Medical Leave Act (FMLA) is a federal program that allows workers to take up to 12 weeks of unpaid leave to care for a family member.

The FMLA applies to employers that meet certain criteria:

- Private-sector employer, with 50 or more employees in 20 or more workweeks
- Public agency, including a local, state, or Federal government agency, regardless of the number of employees it employs.
- Public or private elementary or secondary school, regardless of the number of employees it employs.

An **eligible employee** is one who:

- works for a covered employer.
- has worked for the employer for at least 12 months and has at least 1,250 hours of service for the employer during the 12 month period (the 12 months of employment do not have to be consecutive)

Eligible employees may take up to 12 work weeks of leave in a 12-month period to care for a spouse, son, daughter, or parent who has a serious health condition. For more information, go to [www.dol.gov/agencies/whd/fmla](http://www.dol.gov/agencies/whd/fmla) .



### 3. Managing Care at Home



#### Homecare Resources

Being a **caregiver** for a loved one with cancer can be overwhelming. When your loved one's needs are minor, such as help with transportation and household chores, you may not need additional help. However, sometimes the extent of the support required may require additional help.

High quality **home health care** providers are available to help. Many insurance plans cover home health care. Roswell Park's Case Managers can help you set up any home care needs you have. To contact Case Managers, ask for a referral from your doctor or call 716-845-5735.

#### Consumer Directed Personal Assistance Program (CDPAP)

CDPAP allows those eligible for Medicaid to hire friends and family to care for them in their own home. Caregivers are not required to have certification or licensing and can administer skilled services needed, such as injections. You get to decide who cares for you and the hours that suits your habits. For more information visit [www.health.ny.gov/health\\_care/medicaid/program/longterm/cdpap.htm](http://www.health.ny.gov/health_care/medicaid/program/longterm/cdpap.htm)

#### Assisting Angels

Assisting Angels offers general daily assistance for seniors in need; services are non-medical and include transportation, medication management, meals. For more information call **716-741-1330**.

#### Cleaning for a Reason

Cleaning for a Reason provides free home cleaning to patients battling cancer; Visit their website to apply. [www.cleaningforareason.org](http://www.cleaningforareason.org)

#### Preventing Infection at Home

Cancer can cause weakened immune systems in cancer patients. This can increase the risk of infection.

##### How to Prevent Infection

Hand washing is one of the best methods to prevent an infection from spreading. It is important for healthcare providers, caregivers, family, and visitors to wash or sanitize their hands.

Vigorously wash your hands with soap and water for 20 seconds, making sure to wash your thumbs, fingertips and in between your fingers.

If your hands are not visibly soiled or soap and water are not available, using an alcohol based hand sanitizer is okay.

## When to Wash Hands

- Before eating, drinking, or taking medication
- After using the bathroom, coughing, sneezing, or blowing your nose
- Before touching your eyes, nose, mouth, or contact lenses.
- Before and after performing any care with your central lines, catheters, and dressings (wound care)
- After touching things in the environment that are frequently touched by others

Good personal hygiene will also help keep everyone safe from infections:

- Bathe or shower regularly using a mild soap.
- Change your towels daily and do not share towels.
- Check your skin closely for rashes, redness, signs of infection, or cuts that don't heal.
- Use a soft toothbrush to clean your teeth after meals and before going to bed.
- Be sure to keep any wound dressings dry. If they get wet, change them as soon as possible.

It is also helpful to be aware of the signs for an infection. If your loved one have any of these, call their healthcare team right away:

- Fever
- Cough
- Body aches, fatigue
- Areas of skin that are red, tender or swollen.

Other key points to remember:

- Avoid people who are sick and crowds of people during cold and flu season.
- Get plenty of rest. Fatigue can cause stress on your immune system that can raise your risk of infection.
- Eat a well-balanced diet with proper nutrition.
- If your loved one's immune system has been weakened, their body may need help to protect itself from any bacteria or viruses. Their healthcare provider may suggest they be vaccinated against flu, pneumonia, or COVID. It is also a good idea for caregivers and close family members to be vaccinated as well to further reduce any risks to the patient.

## Transportation

Transportation to and from healthcare appointments is a necessary part of the healthcare process, but it can create many challenges for the patient and their caregivers. Here are some programs that may help you:

**American Cancer Society Road to Recovery Program:** This program offers free transportation to and from medical appointments for cancer treatment. This program is staffed by volunteer drivers and is available throughout much of Western New York. Contact ACS for more information [1-800-227-2345](tel:1-800-227-2345)

**Medicaid Transportation:** Medicaid may be able to provide free transportation to healthcare appointments or may help reimburse the cost of mileage, tolls, parking, etc. Applications for Medicaid

transportation assistance require medical certification signed by your primary care doctor and may take a few weeks to process. Call for more information [1-800-651-7040](tel:1-800-651-7040).

If you find that you are unable to access the above services or you are having difficulty with transportation to your appointments, please contact our Social Work Department at [716-845-1300](tel:716-845-1300) ext. 4276.

## **Good Nutrition During Cancer Treatment**

Cancer and cancer treatments may affect taste, smell, appetite, and the ability to eat enough food or absorb the nutrients from food. This can cause malnutrition, which is a condition caused by a lack of key nutrients.

Lack of good nutrition can cause the cancer patient to be weak, tired, and unable to fight infection or finish cancer treatment. Healthy food choices are very important during cancer treatment.

The two main nutrition goals during treatment are:

- Choose foods and beverages that your loved one can tolerate best.
- Aim for choices rich in healthy nutrients to for energy, nutrients to heal, and calories to prevent unintended weight loss.

Eating the right amount of protein and calories is important for healing, fighting infection, and having enough energy.

Our **Registered Dietitians Nutritionists (RDNs)** are part of your Roswell health care team. They can help manage nutrition-related side effects and improve your loved one's nutritional health before, during, and after cancer treatment. If you would like to meet with a dietitian, ask your doctor or nurse to order nutrition consult.

## **Preparing Food Before Treatment Begins**

Talk with your doctor or nurse about eating problems to watch for. Until treatment starts, you will not know what, if any, side effects or eating problems you may have. If you do have problems, they may be mild. Many side effects can be controlled and many problems go away when cancer treatment ends.

Here are some ways you can get ready to eat well during cancer treatments:

- Fill the refrigerator, cupboard, and freezer with healthy foods. Make sure to include items you can eat even when you feel sick.
- Stock up on foods that need little or no cooking, such as healthy frozen dinners and ready-to-eat cooked foods.
- Cook foods ahead of time and freeze in meal-sized portions.
- Ask friends or family to help you shop and cook during treatment. Maybe a friend can set up a schedule of the tasks that need to be done and the people who will do them.
- Create a grocery list of items you usually buy so that it is easy for friends and family to shop for you.

During treatment, you loved one may have good days and bad days when it comes to what they are able to eat. Here are some ways you can help them manage:

- Serve them plenty of protein and calories. This helps keep up their strength and helps rebuild tissues harmed by cancer treatment.
- Have them eat when they have the biggest appetite. They may want to eat a bigger meal when they are feeling their best and drink liquid meal replacements when their appetite is low.
- It's okay if they feel like they can't eat a lot of different foods. They can eat the foods that sound good until they are able to eat more, even if it's the same thing again and again. You can offer them protein shakes for extra nutrition.
- Do not worry if they cannot eat at all some days. Tell their doctor if they cannot eat for more than 2 days.
- Have them drink plenty of liquids. It is even more important to have plenty to drink on days when they cannot eat. Drinking a lot helps their body get the liquid it needs. Most adults should drink 8 to 12 cups of liquid a day. Give them a water bottle to help remind them to drink.

### **Food Safety**

A side effect of cancer and cancer treatments is that they may weaken the immune system. This puts cancer patients at a higher risk for infections including those brought on by disease-causing bacteria and other pathogens in foods. To avoid contracting a foodborne illness, be careful when handling, preparing, and consuming foods.

For example, if you are not sure about the safety of a food in your refrigerator, don't take the risk. When in doubt, throw it out! Never taste a food to determine if it is safe to eat.

### **Resources for Better Nutrition**

All these resources and more are available to you at no cost in the **11 Day Power Play Cancer Resource Center** on the 1<sup>st</sup> floor of our main hospital. Call 716-845-8659, option 1, for more information.

**Eating Hints Before, During, and After Cancer Treatment**, NIH Document 22-7157. ©2022

<https://www.cancer.gov/publications/patient-education/eatinghints.pdf>

**Eating Well Through Cancer: Easy Recipes & Recommendations During & After Treatment**, by Holly Clegg, ©2006

**Good Nutrition During Cancer Treatment**, ©2021 Roswell Park Patient Education and Nutrition Department.

## 4. Accepting Help from Friends and Family



Many caregivers say that, looking back, they realize they took too much on themselves and wish they had asked for help from friends or family sooner.

What things would you like help with? What tasks can you turn over or share with people?

Accepting help from others isn't always easy. But remember that getting help for yourself can also help your loved one—you may stay healthier, your loved one may feel less guilty about all the things that you're doing, some of your helpers may offer useful skills and have extra time to give you.

One caregiver suggested writing chores you need help with on Post-It® notes and place them somewhere in your house such as on your refrigerator. When friends or family visit and ask what they can do to help, they can choose a task from the notes.

Here are some ideas of what you may need help with and what family or friends would be willing to do for you:

- **Meals:** Make a list of foods your loved one prefers, and foods that are approved by their healthcare team. When someone asks to bring a meal or some snacks, have the suggestions ready.
- **Rides:** Ask friends or family members to drive your loved one to and from appointments.
- **Companionship:** Cancer patients have many appointments and some days are long. Ask friends or family members to help keep the patient company during these times.
- **Shopping:** Keep a list of things you or your loved one needs from the store and ask friends or family to pick up a couple of items the next time they are at the store.
- **Household chores:** Suggest friends or family members help with chores such as childcare, pet care, house cleaning, laundry, etc.
- **Gift certificates:** Gift certificates are always welcome to restaurants, meal delivery services, ride sharing programs such as Uber or Lyft, books, movies, streaming services, magazines, spa treatments, etc.
- **Organizing help:** Ask someone to help you organize the help offered. They can be the contact person for those who want to know how they can help and keep a list of needs and schedule meals and rides. There are also websites such as Sign Up Genius <https://www.signupgenius.com> or Lotsa Helping Hands <http://lotsahelpinghands.com> that can help you organize requests and tasks.



## 5. Managing Your Emotions

Caregiving is hard work that can affect your emotional wellbeing. Taking care of yourself includes coping with many of your own feelings that come up as you care for your loved one. Many people feel more emotional than usual when they are coping with a loved one's cancer. This is normal.



When caring for a loved one with cancer, caregivers may feel:

- **Guilt:** Sometimes caregivers feel guilty that they are healthy. Others may feel badly about enjoying things in life that their loved one cannot. It is also common for caregivers to feel that they are not doing enough to help.
- **Anger:** Caregivers may feel angry with the cancer itself, or with themselves, their loved one, family members, doctors or others. Pinpointing the source of the anger can help you better manage the feeling.
- **Sadness:** It's natural to feel sad when someone you love is seriously ill. You might also miss the life the two of you had before cancer.
- **Worry:** At times, you may feel tense, nervous, or scared or have difficulty relaxing. This is normal. Examples of things caregivers often worry about include their loved one's health, paying the bills and how other family members are coping.
- **Discouragement:** Being a caregiver can sometimes feel like a long, bumpy road. It's easy to get discouraged from time to time. This is especially true if your loved one's condition turns worse.
- **Feeling overwhelmed:** It is common to feel overwhelmed as a caregiver. Providing practical and emotional support to someone with cancer can feel like a full-time job.

You cannot make difficult feelings go away, but there are things you can do to feel better. Here are some tips for coping with the emotional impact of your loved one's cancer:

- **Take a break:** If possible, take some time out for yourself regularly. Even if it's just for a few minutes, doing something you enjoy can help you recharge. For example, listening to relaxing music or taking a walk might help you clear your head.
- **Be aware of your limits:** Remember that there are only so many hours in a day. Feel free to say "no" when people ask you to take on tasks you don't have the time or energy to complete.
- **Keep a journal:** Writing sometimes helps people organize their thoughts and come up with practical solutions. Writing about your thoughts, feelings and memories can also strengthen your spirit.
- **Open up to friends and family:** Ask friends or family members if they would be willing to be "on call" in times of stress. Or plan a regular "check-in" time when you can get together or call each other.



## 6. Taking Care of Yourself



### Caregiver's Bill of Rights

As a caregiver, you try to strike a balance each day. You care for your loved one while keeping up with the demands of family and work. Your focus tends to be on the patient's needs. But it's also up to you to try to stay in tune with yourself.

Giving care and support during this challenging time isn't always easy. The natural response of most caregivers is to put their own feelings and needs aside. They try to focus on the person with cancer and the many tasks of caregiving. This may be fine for a short time. But it can be hard to keep up for a long time. And it's not good for your health. If you don't take care of yourself, you won't be able to take care of others. It's important for everyone that you also take care of YOU.

- I have the right to **take care of myself**. This is not an act of selfishness. It will give me the ability to take better care of my loved one.
- I have the right to **seek help from others** even though my loved one may object. I know the limits of my own endurance and strength.
- I have the right to **maintain parts of my own life** that do not include the person I care for, just as I would if they were healthy. I know that I do everything that I reasonably can do for this person. I have the right to do something just for myself.
- I have the right to get angry, be depressed and **express difficult feelings once in a while**.
- I have the right to **reject the attempt** by my loved one to make me do things out of guilt or anger. (It doesn't matter if they know they are doing it or not.)
- I have the right to **get consideration, affection, forgiveness and acceptance** for what I do for my loved one, as I offer these in return.
- I have the right to **take pride in what I am doing**. And I have the right to applaud the courage it has taken to meet the needs of my loved one.
- I have the right to **protect my individuality**. I also have the right to a life that will sustain me in times when my loved one no longer needs my full time help.

*\*©2014 National Cancer Institute "When Someone You Love is Being Treated for Cancer"*

## Caring for Yourself

It is common for caregivers to provide excellent care for others but neglect their own health. It may be challenging to find the time and energy to care for yourself, but it can help you become a better caregiver.

Here are a few tips to help you stay healthy, organize the chaos, and manage your stress.

- Be kind to yourself. Do something for yourself each day, even if just for a few minutes.
- Stay physically active. Even light exercise such as walking can improve mood and reduce stress.
- Find ways to connect. Share your feelings with a supportive friend or fellow caregiver. Join the Roswell Park online community at [www.cancerconnect.com/roswellpark](http://www.cancerconnect.com/roswellpark) or a caregiver support group.
- Stay away from people with negative attitudes.
- Seek diversion – see friends, laugh, see a movie, take up a hobby, and **rest**.
- Set priorities and timetables. Break down large tasks into smaller parts.
- Make healthy food choices – less salt, sugar, saturated fats, and processed foods, and more whole grains, fruits, vegetables, and water. Poor nutrition can affect how you feel and increase your risk of getting sick.
- Learn to accept offers of help and to ask for help.
- Say “no” when you can. Be realistic about your time and energy, don’t overdo.
- If you are a sole caregiver, talk with a Patient Navigator or a Social Worker at Roswell Park about respite care programs.

For more information on caregiving, stop in The 11 Day Power Play Resource on the 1st floor of the main hospital, or call 716-845-8659.

## 7. Long-Distance Caregiving

If you live away from your loved one who is going through cancer treatment, there are still things you can do to help:



- Try to learn as much as you can about your loved one’s illness. Ask to be an “Authorized User” on the patients portal, My Roswell, so you can keep up with their treatments.
- Develop a relationship with one or two key members of the health care team, such as a nurse, social worker or patient educator. You could arrange conference calls or online meetings with them and other members of the team for updates.
- Make sure the healthcare team has your home, work, and cell phone numbers, and email address.
- Make sure you have written permission to receive medical information and, if necessary, make decisions about your loved one’s care. See section on Power of Attorney and Health Care Proxy.
- Create a list of people who live near your loved one whom you could call day or night in a crisis or just to check in.
- Look into local shopping and meal delivery services for your loved one.
- Sending your loved one a list of questions that you have and ask them to discuss them with their doctors. This can help you to feel involved, gets your questions answered and also reminds the patient that you’re there for them.
- You can help their loved one with day-to-day things to help them get organized:
  - manage their household bills or finances.
  - organize legal paperwork and direct them to resources and information about things like power of attorney, advanced directives, wills and health care proxies.
  - coordinate medical appointments and tests and arrange rides.
  - arrange for local friends and family to drop off meals or help with shopping.



## 8. Caregiver Resources

There are many organizations and websites offering assistance, guidance, and support to caregivers. Here are some you may find helpful:

National Institute on Aging, Caregivers [www.nia.nih.gov/health/caregiving](http://www.nia.nih.gov/health/caregiving)

National Cancer Institute [www.cancer.gov/about-cancer/coping/caregiver-support](http://www.cancer.gov/about-cancer/coping/caregiver-support)

American Cancer Society [www.cancer.org/treatment/caregivers/caregiver-resource-guide.html](http://www.cancer.org/treatment/caregivers/caregiver-resource-guide.html)

Centers for Disease Control [www.cdc.gov/cancer/survivors/caregivers/index.htm](http://www.cdc.gov/cancer/survivors/caregivers/index.htm)

ASCO Cancer.net [www.cancer.net/coping-with-cancer/caring-loved-one](http://www.cancer.net/coping-with-cancer/caring-loved-one)

Cancer Care [www.cancercare.org/tagged/caregiving](http://www.cancercare.org/tagged/caregiving)

Cancer Support Community [www.cancersupportcommunity.org/caregivers](http://www.cancersupportcommunity.org/caregivers)

National Alliance for Caregiving [www.caregiving.org](http://www.caregiving.org)

Family Caregiver Alliance [www.caregiver.org](http://www.caregiver.org)

AARP [www.aarp.org/caregiving](http://www.aarp.org/caregiving)

US Government [www.usa.gov/disability-caregiver](http://www.usa.gov/disability-caregiver)

Centers for Medicaid and Medicare [www.cms.gov/outreach-and-education/outreach/partnerships/caregiver](http://www.cms.gov/outreach-and-education/outreach/partnerships/caregiver)

National Council on Aging <https://ncoa.org/caregivers>

Oncolink [www.oncolink.org/support/caregivers/caregiving-basics](http://www.oncolink.org/support/caregivers/caregiving-basics)

Caregiver Action Network [www.caregiveraction.org/](http://www.caregiveraction.org/)

Leukemia Lymphoma Society [www.lls.org/support-resources/caregiver-support](http://www.lls.org/support-resources/caregiver-support)

**We would like to once again invite you to attend our Caregiver Support Group:**

**March- June & September- December**

**1<sup>st</sup> Thursday of the month**

**1:00p.m. – 2:30p.m.**

**Location: 11 Day Power Play Resource Center**

**1<sup>st</sup> floor near the tower elevators**

**For more information, call 716-845-8051**





