



**Be
Your
Own
Advocate**

Guidebook for Patients

A young boy with brown hair and blue eyes is the central focus, holding a large white sign with the word 'SURVIVING' written in blue, bold, sans-serif capital letters. He is wearing a black t-shirt with 'TEAM PRESTON' printed in purple. The background is a blurred outdoor setting with green grass, trees, and other people, including a woman in a red jacket and a man in a white cap. There are also orange and red balloons visible. The overall atmosphere is positive and supportive.

SURVIVING

Preston,
leukemia survivor

Be
Your
Own
Advocate



Our Mission

*Cure leukemia, lymphoma,
Hodgkin's disease and
myeloma, and improve the
quality of life of patients
and their families.*

Be Your Own Advocate Patient Guidebook

The Leukemia & Lymphoma Society (LLS) is the world's largest voluntary health agency dedicated to blood cancer. LLS funds lifesaving blood cancer research around the world and provides free information and support services.

As part of our support services to individuals newly diagnosed with blood cancer, we have created this personal guidebook to help you navigate the information and details pertaining to your treatment plan. We know it is difficult to keep track of significant data: doctor's appointments, special procedures, test results, insurance documents, receipts for various expenses (co-pays and parking fees) and other items that you accrue with each hospital or physician visit. This guidebook will allow you to be your own advocate.

The Leukemia & Lymphoma Society offers you this guidebook as a personal companion for each treatment-related appointment. Bring it with you to all of your appointments and use it to store any document that belongs to your treatment plan. As a precaution, do not use it to store personal identity documents such as your driver's license, social security, insurance or credit cards. Information that you will find inside includes:

- A monthly calendar to notate all that occurs before, during and after your medical appointments
- A list of frequent questions for you to ask your doctor, with space to take notes
- Easily accessible phone numbers to many local resources
- Additional printed materials with important information related to your treatment
- Pockets in which you can place pertinent treatment information

The Leukemia & Lymphoma Society is here to help you and has many programs to offer to blood cancer patients and their families.

To learn more, visit our local web site:

www.lls.org/ia or call us at **(515) 270-6169** or **(800) 347-1074**.

Your medical team's opinion is valuable. LLS does not offer medical advice or support a specific health care provider or medical facility.

On behalf of the LLS Patient Access Team, we want to express our gratitude for letting us help you during this personal experience.

The Iowa Chapter



LEUKEMIA &
LYMPHOMA
SOCIETY®

fighting blood cancers

2700 Westown Pkwy.
Suite 260
West Des Moines, IA 50266
515-270-6169
www.lls.org/iowa

Be Your Own Advocate

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*Caesar,
leukemia survivor*

**Be
Your
Own
Advocate**

I WALK



1

Your
Healthcare
Team &
Treatment

Healthcare Team Members: Who are they and what are their roles?

The team of healthcare providers who will administer your treatment is sometimes called a “multidisciplinary” team in that they are professionals from across different specialties and departments within the hospital. This dedicated group of professionals works in concert to provide you the best treatment plan. Because they are instrumental to your care, it can be helpful to know more about their specific roles. If you have any questions, don't hesitate to ask members of your healthcare team about their role or the specific care they are providing. Below is a list of various care providers and their roles:

Physicians

Primary care, general practitioner or internal medicine physicians provide general healthcare. They are usually the doctors who refer patients to hematologists and oncologists for treatment of blood cancers. Following completion of your treatment, you will continue to see your primary physician for general healthcare needs.

Physicians receive training at a university or teaching hospital. If you are being treated at one of these facilities, you might encounter the following types of doctors: **attending physicians** have medical degrees and have completed residency training; **fellows** are doing further training in a specialty after having completed medical school and residency training; **residents** work with attending physicians to become certified in a particular specialty after having graduated from medical school and completing an internship; **interns** must be supervised by a senior physician while they train in a general area of medicine following medical school graduation; **medical students** have completed two to three years of medical school and work in hospitals under the supervision of attending physicians.

Anesthesiologists administer drugs or other treatments for pain management, most often during and after surgery, as well as other procedures.

Hematologists, medical oncologists and radiation oncologists are physicians specializing in cancer treatment.

Physiatrists are certified in physical medicine and rehabilitation and work with patients dealing with physical impairment and the loss of function.

Physician's Assistants (PAs) are licensed to practice specific aspects of medicine under the supervision of a physician.

Pathologists study cells and tissues, and interpret lab test results to confirm a patient's diagnosis.

Surgeons or surgical oncologists can operate and usually specialize in the surgical removal of cancer.

Nurses

Registered nurses (RNs) have completed a specific amount of training and have a nursing degree. RNs provide care under the order of a physician, nurse practitioner or a physician's assistant. Many RNs are certified in caring for patients in a particular specialty, such as oncology.

Nurse practitioners (NPs) or advanced practice nurses (APNs) are registered nurses who have completed graduate-level studies in nursing and have advanced training in a specific field, such as oncology. NPs and APNs work closely with physicians, and can prescribe medications, as well as diagnose, treat and manage a patient's care.

Certified nursing assistants (CNAs) have completed a specific amount of training and are supervised by nurses or other medical staff. CNAs provide practical care, such as help bathing.

Other Healthcare Team Members

Case managers or care managers guide patients from diagnosis through treatment, providing cohesion to other professionals on your healthcare team.

Chaplains provide spiritual support to patients and families. Most hospitals employ chaplains from a variety of faith backgrounds and denominations.

Child Life Specialists use their knowledge of child development to help prepare and support children and their families through various components of diagnosis and treatment. They promote the involvement of parents or other family members as partners with the child's healthcare team.

Dietitians or nutritionists are food and nutrition experts who help guide and counsel patients on nutritional eating.

Occupational therapists (OTs) are trained to help people return to or improve upon activities that are important to everyday living, such as dressing, bathing or working.

Patient navigators support and guide patients through the many components of care from diagnosis through treatment, which can include setting up appointments, referring patients to support services and helping with paperwork. Patient navigators also maintain communication between the patient and other members of his or her healthcare team.

Physical therapists (PTs) provide services to help patients regain function, improve mobility, relieve pain and prevent or limit permanent physical impairment.

Psychiatrists, psychotherapists and psychologists assist patients with mental or emotional challenges that arise from being diagnosed with cancer. Psychiatrists are medical doctors who can prescribe medications.

Social workers provide psychosocial support to patients and their families. They help plan for patients' needs after discharge from hospitals, and may help arrange for at-home services.

Specialty Pharmacies carry more types of prescriptions than chain or neighborhood pharmacies. Some cancer prescriptions can only be filled at these specialty pharmacies. Ask your healthcare team where your prescriptions can be filled.

Talk to your doctor about any clinical trials for which you might qualify, and find out if your doctor recommends them for you.

Participants in clinical trials can play a more active role in their own health care, gain access to new research treatments before they are widely available, and help others by contributing to medical research.

Medical Contacts

Primary Care Physician _____

Telephone _____

Email _____

Nurse _____

Telephone _____

Email _____

Primary Oncologist _____

Telephone _____

Email _____

Oncology Nurse _____

Telephone _____

Email _____

Radiation Oncologist _____

Telephone _____

Email _____

Surgeon _____

Telephone _____

Email _____

Psychologist _____

Telephone _____

Email _____

Hospital _____

Telephone _____

Email _____

Medical Lab _____

Telephone _____

Email _____

Medical Contacts

Primary Care Physician _____

Telephone _____

Email _____

Nurse _____

Telephone _____

Email _____

Primary Oncologist _____

Telephone _____

Email _____

Oncology Nurse _____

Telephone _____

Email _____

Radiation Oncologist _____

Telephone _____

Email _____

Surgeon _____

Telephone _____

Email _____

Psychologist _____

Telephone _____

Email _____

Hospital _____

Telephone _____

Email _____

Medical Lab _____

Telephone _____

Email _____

Working with Your Healthcare Team

Your care and treatment for blood cancer is very much a team effort, and you are the most important member. When you are being treated for cancer, circumstances may seem beyond your control. However, you play an integral part in developing your care plan, along with your physicians and other members of your care team.

Depending on the details of your health insurance, you may have some choice as to which hospital you attend for treatment. It is important for you to feel comfortable with your oncologist and all members of your healthcare team. You should talk freely and in detail about your symptoms, pain and any other changes you notice in your body. Ask any questions that you have regarding all aspects of your treatment. If at any time you feel like your personal style is not a good fit with a member of your team, don't hesitate to share your concerns. Discussing your concerns directly with your healthcare team member is often the best approach, but if you feel uncomfortable, bring your concerns to someone you trust. Many hospitals have patient advocates whose role is to solve problems between patients and healthcare staff.

If you are not feeling well, or if it would make you more comfortable, having someone else with you at appointments might be helpful. Enlist the help of a trusted family member, friend or social worker to accompany you to tests and appointments.

Familiarize Yourself with Policies and Procedures

Equally important to getting to know your healthcare team is learning about all policies and procedures important to the various components of your treatment. Familiarize yourself with what to do in the following situations:

Reaching your physician

You will have needs and concerns that occur outside of regular appointments. Ask your doctor how they prefer to be reached in these situations, such as a phone call, email, answering service or paging system. Find out how your physician handles emergencies when they are not available. Most physician offices recommend patients go to the hospital emergency room or dial 911.

Obtaining Test Results

To reduce the anxiety that waiting can cause, ask how you should obtain test results. Physician offices vary as to whether they contact you with the results or ask that you call into their office. In most instances, your physician will want to discuss the results with you. You should always feel free to ask questions until you understand the results. Be sure to reference the Understanding Lab and Imaging Tests booklet in the back of this guidebook.

Confidentiality

Healthcare providers are required to protect the privacy of patients under the Health Insurance Portability and Accountability Act (HIPAA). You will be asked to read and sign a HIPAA form prior to your treatment and to provide the names of people with whom your healthcare information can be shared. Ask questions before signing the forms and find out who else will have access to your information, such as your insurance provider.

Preparing for Appointments

Preparing in advance for doctor appointments can be beneficial to both you and your healthcare team. This guide will provide a list of questions to ask your physician. Prior to your appointments, write down any additional questions you have to share with your doctor. These can include:

- General concerns about your treatment as well as any emotional concerns, such as depression
- Pain, new symptoms or any new side effects you have noticed
- Any other treatments you have had, including a massage or acupuncture
- Current medications (including prescriptions, over-the-counter drugs, vitamins and nutritional supplements) and dosages

Suggested Items to Bring to Appointments

Your course of treatment will include many appointments for tests, to see your doctor or for treatment. To make efficient use of your time as well as stay comfortable during these visits, we have created the following checklists to help you make the most of your appointments, including suggestions on what to bring and what to leave at home.

What to Bring to the Hospital Checklist

- Photo ID (driver's license or state identification card) and insurance card
- Pajamas, nightgown and robe, if you wish
- Personal toiletries, such as shampoo, toothbrush, toothpaste, lotion (hospital rooms tend to be dry)
- Comfortable clothes to wear home
- Money (including change) to purchase newspapers, magazines, etc.
- Assistive devices such as walkers, crutches, canes, hearing aids or magnifying glasses labeled clearly with your name
- A list of prescription medications, dosages and schedule. Ask your physician beforehand if you should bring any of your medications to the hospital (a page to list medications is included on page 1.6)
- Names and phone numbers of family members or friends to contact in an emergency
- Written list of past hospitalizations, illnesses, surgeries and allergies
- A copy of your Advance Directives, including the Living Will or Durable Power of Attorney for Health Care, if available

Discharge Checklist

The following is designed to help you prepare to leave the hospital:

Review with your physician, nurse or pharmacist all information about the medications and care you will need at home

Pick up any prescriptions that you need from the Professional Building pharmacy

Check your room for any belongings you may have left in the drawers or closet

Pick up any valuables you may have left with the Admitting/Registration Department

Confirm that you have transportation home and that you will be picked up at the appropriate entrance

Infusion and/or Radiation Day Checklist

Infusion therapy and radiation therapy does not require much preparation on your part. However, there are a few things to keep in mind for your treatment day. Use this checklist before each appointment to make sure you are ready:

- Talk to your doctor if you have any questions about your treatment regimen.
- Be sure to tell your doctor or nurse about any concerns you have before beginning your infusion or radiation session.
- Pack something to eat or drink. You may be at the clinic most of the day, so you may want to bring snacks or a prepared meal. Ask your doctor or nurse if there are any special rules about what you should eat or drink before an infusion.
- Bring activities such as crossword puzzles or a book to help you pass the time.
- Arrange transportation. The medications to reduce side effects may make you drowsy or dizzy, so it is a good idea to have someone else drive you home after treatments.
- Remind your doctor or nurse of the medications you take. They may give you special instructions for the day.

Please do not bring:

- Valuables such as, jewelry, credit cards and checkbooks. Most hospitals are not responsible for your belongings. If you must bring valuables, ask to have them deposited in the hospital safe.
- Personal electrical appliances such as heating pads, televisions and radios.

Medications Tracker

Through the course of your treatment you may be prescribed a variety of medications, in addition to any you were taking prior to your diagnosis. The medications you are taking and their doses are critically important to your treatment and it is a good idea to have a list of each type and dosage documented. We have provided these pages to help you keep track.

Date Prescribed	Name of Medication	Dosage

We've listed some questions that are important for you to ask your physician on each visit.

As a suggestion, write down your own questions before your appointment to ensure all your concerns are addressed each time. Additional questions can be found in the education resources section at www.lls.org/whattoask.

Questions to Ask to Your Doctor

Date of visit _____

Dr. _____

1. What does my blood analysis show?

2. When should I repeat blood work?

3. Can I get a copy of these tests for my records?

4. What other exams should I need and when?

5. I've experienced the following symptoms prior to my visit.
What's the reason?

6. What can I do to control these symptoms?

7. How is the progress of my disease?

8. Am I going to have a change in my treatment schedule,
dose or medication? Why?

9. What kind of medication do I need to take at home and how often?

10. Why do I have to take them?

11. Is there anything I should avoid?

What kind of precautions do I need to take at home?

12. What exactly is my diagnosis?

13. What's the goal of treatment – to cure or to control my symptoms?

14. Are you the right doctor to treat my specific disease?

15. How much experience do you have treating patients with my disease?

16. What options are available for my diagnosis?

17. Can I get written information about my illness and treatment?

18. What is the stage, type and spread of my cancer and what does this mean for me?

19. Can I participate in a clinical trial? If so, what is the trial testing? What are my benefits and risks?

20. How should I prepare for this financially?

21. Is this type of cancer caused by genetic factors? Are other members of my family at risk?

22. Where can I find more information about my type of cancer?

23. What lifestyle changes – such as diet, exercise, and rest – do you recommend I make to stay as healthy as possible before, during, and after treatment?

24. What's the best time to call you if I have a question?

25. What are the chances that the cancer may come back with the treatment plans we've discussed? What would we do if that happens?

26. How do I reach you after hours or on weekends and holidays if necessary?

Asking your healthcare provider questions can help you take an active role in managing your care. If you do not understand any part of the information your healthcare provider gives you, ask him or her to explain it in another way.

Questions About Taking Medications at Home

Doctor's Name _____

Name of Medication _____

Date of appointment or call _____

1. What if I miss a dose?

2. What if I vomit right after I take my medication?

3. Is it okay to drink alcohol during my treatment?

4. When should I take my medication?

5. For how long do I take my medication?

6. How should I store my medication?

7. Do I need to take this medication with food?

8. Are there any potential drug interactions?

9. What are the possible side effects of this medication?

10. What should I do if I experience an unexpected side effect to this medication?

11. What can I do to relieve the side effects?

12. How does the medication work?

13. Will this medication cause drowsiness or affect my alertness?

14. Can I crush my pills?

15. Is it required to avoid strong sunlight or tanning beds while taking this medication?

16. Is there a proper way to dispose any additional or unwanted medication?

Notes

Please write down your own questions and the answers:

Asking your healthcare provider questions can help you take an active role in managing your care. If you do not understand any part of the information your healthcare provider gives you, ask him or her to explain it in another way.

Questions About Treatment Side Effects

Doctor's Name _____

Date of appointment or call _____

1. What are common side effects of this treatment?

2. What are less common side effects of this treatment?

3. How will the treatment affect my sexual health?

4. How will my treatment affect my menstrual cycle?

5. Will treatment side effects change my appearance? If so, will the changes be permanent or temporary?

6. Will my treatment cause any sleeping problems, such as insomnia?

7. How long will the side effects most likely last?

8. When should I contact a member of my health care team about a side effect?

9. When are side effects likely to happen?

10. Are there any side effects I should tell my doctor about right away?

11. What can I do to ease side effects?

12. How will my treatment affect fertility, pregnancy or breastfeeding?

13. What are the long-term and late effects of my treatment?

Notes

Please write down your own questions and the answers:

Handwriting practice area consisting of multiple horizontal yellow lines.



A close-up portrait of a woman with voluminous, curly brown hair, smiling warmly at the camera. She is wearing large hoop earrings and a necklace made of white, shell-like pieces. The background is a plain, light color.

Shelia

lymphoma survivor

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A woman with curly hair is shown from the side, with her shoulder and a tattoo visible. A large, light purple teardrop-shaped graphic is overlaid on the image, containing the number '2' and the text 'Your Support System'. A solid purple shape is also present on the right side of the image.

2

Your Support System

How Your Support System Can Help

Following a diagnosis of cancer, you may find support from family, friends and loved ones who rally around you. Or you may choose to keep your diagnosis and treatment very private. How you choose to deal with your diagnosis and treatment is an extremely individual choice. However, there may be times when extra support is needed. A support system composed of friends, family and/or organizations with experience in helping people through medical challenges can assist with a variety of needs, from practical tasks like housekeeping, meal preparation and navigating insurance issues to the emotional support of an attentive ear to listen to your concerns.

Members of your support system can help you by:

- Assisting with day-to-day needs (meal preparation, housekeeping, laundry, etc.)
- Setting up child care services or transportation
- Researching information and finding services you need
- Finding help for insurance and financial matters
- Keeping track of your healthcare needs and appointments
- Talking with your healthcare team on your behalf, particularly at times when you may not feel physically or emotionally up to the task
- Being a supportive listener if you need help solving a problem or if you feel the need to share concerns about the day-to-day impact of your diagnosis and treatment

Organizing Your Support System

Although it might be difficult or uncomfortable to ask for help, you will find that most people feel good about helping others, particularly if that person is a family member, friend or neighbor who cares about you. Remember that in a similar situation you would probably want to do the same thing for a family member or loved one.

To foster appropriate personal boundaries and to make sure you're getting help with what you really need, here are some ideas for organizing your support system:

- Create a list of tasks that others can help you complete
- Make a list of people who can provide help and support
- Contact your list of potential support system members; ask when and how they would be willing to help
- Create a schedule with dates, times, tasks and names of people who have agreed to help (see our sample schedule).
- Keep the schedule and share copies with your support system members.

The chart on pages 2.2 - 2.3 can help you to organize the tasks for which you need help, who can assist you and when assistance is needed.

Online Resources to Assist with Your Support System

There are a number of online resources that let you create web pages to keep friends and family updated on your health status, share any needs you might have and allow these important people to send you words of encouragement. Here are a few examples. Also, please see the "Resource Tab" of this guidebook for other useful referrals and resources.

Lotsa Helping Hands

www.lhs.lotsahelpinghands.com

Lotsa Helping Hands is a simple, immediate way for friends, family, colleagues and neighbors to assist loved ones in need.

It's an easy-to-use, private group calendar, specifically designed for organizing helpers, where everyone can pitch in with meal delivery, rides and other tasks necessary for life to run smoothly during times of medical crisis, end-of-life caring, or family caregiver exhaustion. It's also a place to keep these 'circles of community' informed with status updates, photo galleries, message boards, and more.

Care Pages

www.carepages.com

CarePages.com is an online community of people who come together to share the challenges, hopes and triumphs of anyone facing a life-changing health event. Through personalized websites, members can relate their stories, post photos and update friends and family instantly. In turn, supporters can send messages of love and encouragement. Care Pages also offers a variety of resources and support tools for living a more compassionate life.

CaringBridge

www.caringbridge.org

CaringBridge provides free websites that connect people experiencing a significant health challenge to family and friends, making each health journey easier. CaringBridge websites offer a personal and private space to communicate and show support, saving time and emotional energy when health matters most. The websites are easy to create and use. Authors add health updates and photos to share their story while visitors leave messages of love, hope and compassion in the guestbook.

Help Needed	Days Help is Needed	Times Help is Needed	Helper's Name/Contact Information	Notes/Instructions
Accompany to Medical Appointments				
Cargiving				
Child Care				
Cleaning/ Household Chores				
Help with Insurance Questions				
Help with Bill Payment Questions				

Help Needed	Days Help is Needed	Times Help is Needed	Helper's Name/Contact Information	Notes/Instructions
Laundry				
Meal Preparation				
Pet Care				
Shopping				
Transportation				
Other				

Important Contact Information for Members of Your Support Team

This information may come in handy if members need to contact each other pertaining to their care assignments.

Name _____
Relationship _____
Telephone _____
Email _____

Name _____
Relationship _____
Telephone _____
Email _____

Name _____
Relationship _____
Telephone _____
Email _____

Name _____
Relationship _____
Telephone _____
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Email _____

Name _____
Relationship _____
Telephone _____
Email _____

Name _____
Relationship _____
Telephone _____
Email _____

Name _____
Relationship _____
Telephone _____
Email _____



Jodi

leukemia survivor

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3

Organizing & Planning Calendars

Calendars

To help with the organization and planning around your treatments, we are including a monthly calendar. It offers space to write down any kind of event that happened before, during and after your treatment that you would like to share with your physician.

Being organized is quite important, but it can be time consuming, especially if you are not feeling well during your treatment process. You can designate a member of your support team, to do this job instead if it gets to be overwhelming.

To use this calendar, refer to a preprinted calendar or datebook and note the year, month and dates on the blank calendar pages, as shown to the right. Add notes for important appointments, events, tasks or records. Copy and reuse blank calendar pages as needed.

Appointments and Events

Year 2016

Month

January

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
	1	2	3	4	5	6
7	8	9 <i>Oncologist Appt. - 10 am</i>	10	11	12	13 <i>Prescription Pick Up</i>
14	15	16	17	18 <i>Radiation Treatment 3 pm</i>	19	20
21	22	23	24	25	26	27
28	29	30	31			

Record special concerns, events or symptoms that you experienced during this particular period, so you can share this information with your doctor each time you visit the hospital.

Date:

Notes:

Record special concerns, events or symptoms that you experienced during this particular period, so you can share this information with your doctor each time you visit the hospital.

Date:

Notes:

Record special concerns, events or symptoms that you experienced during this particular period, so you can share this information with your doctor each time you visit the hospital.

Date:

Notes:



Record special concerns, events or symptoms that you experienced during this particular period, so you can share this information with your doctor each time you visit the hospital.

Date:

Notes:

Record special concerns, events or symptoms that you experienced during this particular period, so you can share this information with your doctor each time you visit the hospital.

Date:	Notes:



Record special concerns, events or symptoms that you experienced during this particular period, so you can share this information with your doctor each time you visit the hospital.

Date:

Notes:

Appointments and Events

Month

Year

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday

Appointments and Events

Month

Year

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday

Record special concerns, events or symptoms that you experienced during this particular period, so you can share this information with your doctor each time you visit the hospital.

Date:

Notes:

Record special concerns, events or symptoms that you experienced during this particular period, so you can share this information with your doctor each time you visit the hospital.

Date:

Notes:

Record special concerns, events or symptoms that you experienced during this particular period, so you can share this information with your doctor each time you visit the hospital.

Date:

Notes:

Record special concerns, events or symptoms that you experienced during this particular period, so you can share this information with your doctor each time you visit the hospital.

Date:

Notes:

Weekly Schedules

Use this section to record and/or keep track of things that recur on a weekly basis. Medications you need to take, your medical appointments, your kids' activities, rides or meals needed, etc.

You may choose to photocopy the blank pages or to write in pencil so you can make updates as your regular schedule changes.

	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
6:00 am							
7:00 am							
8:00 am							
9:00 am							
10:00 am							
11:00 am							
12:00 pm							
1:00 pm							
2:00 pm							
3:00 pm							
4:00 pm							
5:00 pm							
6:00 pm							
7:00 pm							
8:00 pm							
9:00 pm							
10:00 pm							

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	
							6:00 am
							7:00 am
							8:00 am
							9:00 am
							10:00 am
							11:00 am
							12:00 pm
							1:00 pm
							2:00 pm
							3:00 pm
							4:00 pm
							5:00 pm
							6:00 pm
							7:00 pm
							8:00 pm
							9:00 pm
							10:00 pm

	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
6:00 am							
7:00 am							
8:00 am							
9:00 am							
10:00 am							
11:00 am							
12:00 pm							
1:00 pm							
2:00 pm							
3:00 pm							
4:00 pm							
5:00 pm							
6:00 pm							
7:00 pm							
8:00 pm							
9:00 pm							
10:00 pm							

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	
							6:00 am
							7:00 am
							8:00 am
							9:00 am
							10:00 am
							11:00 am
							12:00 pm
							1:00 pm
							2:00 pm
							3:00 pm
							4:00 pm
							5:00 pm
							6:00 pm
							7:00 pm
							8:00 pm
							9:00 pm
							10:00 pm



	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
6:00 am							
7:00 am							
8:00 am							
9:00 am							
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Grace
lymphoma survivor

Be
Your
Own
Advocate



4

**Healthcare
Insurance &
Benefits**

Healthcare Insurance & Benefits

Your care and treatment will generate a large amount of paperwork in the form of invoices from healthcare providers and EOB's (Explanation of Benefits) from your insurance company on the various medical services you receive. The nuances of your insurance plan and keeping track of whether these services have been paid - either by you or by your insurer - can be confusing.

To help ease the stress of this challenging, but important, component of your care, we have included definitions of common insurance terms that may be new to you. Italicized words are defined elsewhere on the page.

We have also created a chart to help track the various services for which you are billed. Feel free to use the spreadsheet provided here, or if you would like to keep track on your computer, we recommend setting up an excel spreadsheet similar to the chart on page 4.3. Some insurance providers will allow you to download your EOBs by date range into an excel spreadsheet, which decreases the amount of data entry.

You can find other helpful resources at www.LLS.org/resourcecenter.

Insurance Definitions

Coinsurance

A percentage of each claim above the deductible paid by the patient. For example, in a 20% health insurance coinsurance clause, the patient first pays the deductible (which is usually a fixed amount), and then 20% of the bills thereafter - up to a maximum out-of-pocket expense. Coinsurance percentages may differ for different providers (in-network vs. out-of-network) and/or for different types of services.

Copayment

A predetermined, flat fee a patient pays for healthcare services, in addition to what insurance covers. For example, some plans require a \$20 copayment for each office visit, regardless of the type of level of services provided during the visit. Copayments are not usually specified by percentages. There may be separate copayments for different services. Some plans require that a deductible first be met for some specific services before a copayment applies.

Deductible

A fixed dollar amount during the benefit period (usually a year) that the patient pays before the insurer starts to make payments for covered medical services. Plans may have both per individual and per family deductibles. Some plans may have separate deductibles for specific services. For example, a plan may have a hospitalization deductible per admission. Deductibles may differ if services are received from an approved provider or if received from providers not on the approved list.

Explanation of Benefits (EOB)

A document provided by your insurance plan that explains how much was charged for each service, how much the insurance plan will pay, and how much the patient will be required to pay. When you receive a bill from your physician or hospital, look at the EOB for that service and make sure you are being charged the correct amount.

Lifetime Maximum

The maximum amount payable by the insurer for covered expenses for the insured and each covered dependent while covered under the health plan. The most typical lifetime maximum is \$1 million per individual.

Managed Care Provisions

Features within health plans that provide insurers with a way to manage the cost, use and quality of healthcare services received by patients. Examples of managed care provisions include:

- Preadmission certification: An authorization for hospital admission given by a healthcare provider to a patient prior to their hospitalization. Failure to obtain a preadmission certification in non-emergency situations reduces or eliminates the healthcare provider's obligation to pay for services rendered.
- Utilization review: The process of reviewing the appropriateness and quality of care provided to patients. Utilization review may take place before, during, or after the services are rendered.

- Preadmission testing: A requirement designed to encourage patients to obtain necessary diagnostic services on an outpatient basis prior to non-emergency hospital admission. The testing is designed to reduce the length of a hospital stay.
- Non-emergency weekend admission restriction: A requirement that imposes limits on reimbursement to patients for non-emergency weekend hospital admissions.
- Second surgical opinion: A cost-management strategy that encourages or requires patients to obtain the opinion of another doctor after a physician has recommended that a non-emergency or elective surgery be performed. Programs may be voluntary or mandatory in that reimbursement is reduced or denied if the participant does not obtain the second opinion. Plans usually require that such opinions be obtained from board-certified specialists with no personal or financial interest in the outcome.

Maximum Out-of-Pocket Expense

The maximum dollar amount a patient is required to pay out-of-pocket during a year. Until this maximum is met, the plan and patient share in the cost of covered expenses, often up to a lifetime maximum.

Premium

The dollar amount you pay every month to your health insurance company, even when you do not go see your doctor.

The Affordable Care Act

In 2014, the Patient Protection and Affordable Care Act, commonly known as Obamacare, came into effect. The goal of the law is to give patients the stability and flexibility they need to make informed choices about their health. Below we have listed some key features of the Affordable Care Act, as provided by HHS.gov.

- Ends pre-existing condition exclusions for children: Health plans can no longer limit or deny benefits to children under 19 due to a pre-existing condition
- Keeps young adults covered: If you are under 26, you may be eligible to be covered under your parent's health plan
- Ends arbitrary withdrawals of insurance coverage: Insurers can no longer cancel your coverage just because you made an honest mistake
- Guarantees your right to appeal: You now have the right to ask that your plan reconsider its denial of payment
- Ends lifetime limits on coverage: Lifetime limits on most benefits are banned for all new health insurance plans
- Reviews premium increases: Insurance companies must now publicly justify rate hikes
- Helps you get the most from your premium dollars: Your premium dollars must be spent primarily on health care - not administrative costs
- Protects your choice of doctors: Choose the primary care doctor you want from your plan's network
- Removes insurance company barriers to emergency services: You can seek emergency care at a hospital outside of your health plan's network

Health Insurance Marketplace

Everyone is required to have health insurance under the new healthcare law, the Affordable Care Act (Obamacare). However, you can't just go out and buy it any time you want. There's a limited open enrollment period during which you can sign up for a new plan or change your current plan.

The only exception to that is if you experience certain life-changing events, such as divorce, pregnancy, the loss of employer-provided coverage, or a qualified hardship.

If you do not have health insurance, then you can purchase insurance on the Health Insurance Marketplace. You can also purchase insurance on the marketplace if the company that you work for gives you insurance and you are not happy with it.

For information on enrollment, go to www.healthcare.gov.

Health insurance plans and network types: HMO, PPO, EPO, and POS

Depending on what is offered in your area, you may find coverage in all plan types. You will want to comparison shop for your health insurance coverage, which is divided into four tiers:

- Platinum plans will cover 90% of a person's health care costs
- Gold plans will cover 80% of a person's health care costs
- Silver plans will cover 70% of a person's health care costs
- Bronze plans will cover 60% of a person's health care cost
- Catastrophic plans will be available to only individuals under the age of 30 or those who are exempt from purchasing coverage. The out of pocket limits of \$6,350 individual and \$12,700 family will apply. No cost sharing is required.

Some examples of plan types you'll find in the Marketplace:

- **Exclusive Provider Organization (EPO):** A managed care plan where services are covered only if you use doctors, specialists, or hospitals in the plan's network, except in an emergency.
- **Health Maintenance Organization (HMO):** A type of health insurance plan that usually limits coverage to care from doctors who work for or contract with the HMO. It generally won't cover out-of-network care except in an emergency. An HMO may require you to live or work in its service area to be eligible for coverage. HMOs often provide integrated care and focus on prevention and wellness.
- **Point of Service (POS):** A type of plan where you pay less if you use doctors, hospitals, and other health care providers that belong to the plan's network. POS plans require you to get a referral from your primary care doctor in order to see a specialist.
- **Preferred Provider Organization (PPO):** A type of health plan where you pay less if you use providers in the plan's network. You can use doctors, hospitals, and providers outside of the network without a referral for an additional cost.

Consider Out-of-Pocket costs

In general, the more you are willing or able to pay out-of-pocket each time you need health care services, the lower your monthly premium payment will be. Usually bronze plans have lower premiums and higher out-of-pocket costs, and platinum plans have higher premiums and lower out-of-pocket costs.

Patients should be sure to look at all the out-of-pocket costs associated with the plans at the lower metal tiers. They will likely include high deductibles, sometimes as much as \$5,000 or \$6,000 at the bronze level. Carriers differ regarding whether or not medications are subject to the deductibles, which is another key feature to ask about.

If you rely heavily on products that are a part of the pharmacy benefit, also look for whether these plans have co-insurance, which requires you to pay a

percentage of the cost of the drug or service and can add up to hundreds or thousands of dollars per month. As a cancer patient, or any patient with high cost medical needs, this quickly becomes unaffordable.

What if I can't afford these costs?

When you buy your insurance from the Marketplace, you may be eligible for financial help to lower the cost of coverage. Financial help is available in the form of tax credits to help pay for monthly premium costs. You may also be eligible for financial help to lower the amount you pay for out-of-pocket costs, making your health insurance more affordable.

LLS wants your feedback

The Leukemia & Lymphoma Society is committed to removing access barriers for blood cancer patients. If you purchase a marketplace plan and later experience high treatment costs, a lack of access to your provider or hospital, or a delay in getting timely care, please share your story with us at missioncommunications@lls.org. If you have a positive experience, we would like to hear that too. Making your voice heard can really make a difference.

If you have questions or want more information, please contact LLS's Information Resource Center (IRC) at 1-800-955-4572, Monday to Friday, 9 a.m. to 9 p.m. ET.

Helpful links

<http://obamacarefacts.com/>

<http://obamacare.com/>

<http://obamacare-guide.org/>

Reference Sources

Survey definitions from:

- The National Compensation Survey definitions (BLS)
- The Medical Expenditure Panel Survey definitions (AHRQ)
- The National Employer Health Insurance Survey (NCHS)

Definitions from other Federal agencies and surveys such as:

- The Current Population Survey (BLS/Census)
- Erisa-related definitions (from PWBA)

Glossaries and informational papers from websites such as:

- OPM's Federal Employees Health Benefits Plan (glossary and specific plan booklets)
- Blue Cross/Blue Shield
- The National Center for Policy Analysis
- The Health Insurance Association of America

Publications such as:

- Employee Benefit Plans: A Glossary of Terms, Ninth Edition 1997, Judith A. Sankey, editor, International Foundation of Employee Benefit Plans
- Fundamentals of Employee Benefit Programs, Fourth edition
- Managed Care Plans and Managed Care Features: Data from the EBS to the NCS

Benefits Tracker

Date of Medical Service	Medical Provider/Service Rendered	Total Amount Billed for Service	Amount of Co-Pay/Date Paid	Amount Paid by Primary Insurer or Benefit Program	Amount Paid by Secondary Insurer or Benefit Program	Balance Due	Paid

Benefits Tracker

Date of Medical Service	Medical Provider/Service Rendered	Total Amount Billed for Service	Amount of Co-Pay/Date Paid	Amount Paid by Primary Insurer or Benefit Program	Amount Paid by Secondary Insurer or Benefit Program	Balance Due	Paid

Benefits Tracker

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Benefits Tracker

Date of Medical Service	Medical Provider/Service Rendered	Total Amount Billed for Service	Amount of Co-Pay/Date Paid	Amount Paid by Primary Insurer or Benefit Program	Amount Paid by Secondary Insurer or Benefit Program	Balance Due	Paid

Mark

Mark, lymphoma survivor

SURVIVOR

Be
Your
Own
Advocate

Martez

leukemia survivor

5

Resources

SURVIVOR

*The Leukemia & Lymphoma Society's
Patient Access Support & Programs*

The Leukemia & Lymphoma Society's Iowa Chapter offers a wide range of free educational and support programs for patients, their families, caregivers and healthcare professionals.

Except where indicated, for more information contact the Iowa Chapter at (515) 270-6169 or toll free (800) 347-1074, email Josh.Bollam@lls.org or visit our website at www.lls.org/ia.

Information Resource Center (800) 955-4572

The Information Resource Center is staffed by Information Specialists, master's level oncology professionals. They provide accurate up-to-date disease and treatment information and are available to speak with callers Monday through Friday, 9 a.m. to 9 p.m. ET at (800) 955-4572. You can email infocenter@LLS.org or chat live with a Specialist at www.LLS.org.

Susan Lang Pay-it-Forward

The Leukemia & Lymphoma Society's (LLS) Susan Lang Pay-It-Forward Patient Travel Assistance program is available to blood cancer patients, with significant financial need, who may qualify to receive financial assistance for approved expenses including: ground transportation (gas, tolls, car rental, taxi, bus, train, ambulance services, etc.), air travel, and lodging related expenses. For eligibility and details please call 844-565-2269 or email patientassistance@lls.help.

Co-Pay Assistance Program

This program offers assistance for financially eligible patients with certain blood cancer diagnoses to help pay for private or public health insurance premiums and/or co-pay costs for prescription medications. Visit www.LLS.org/copay or call (877) 557-2672 to speak to a Co-Pay Assistance Program specialist for more eligibility information.

Patti Robinson Kaufmann First Connection Program

This program offers peer to peer support from a well-trained volunteer who has been through a similar situation. The volunteer's own personal experience enables them to relate in a unique and positive way to others who are newly diagnosed. Contact us at (914) 821-8409 for more information.

Trish Green Back to School Program

This back to school program helps children with cancer return to school by providing information to parents, patients, teachers, and classmates. Specially developed material will assist in the transition back to the classroom. Program videos and materials are available for students from preschool to high school. For more information, call us at (914) 821-8409.

Family Support Groups

Our monthly Family Support Groups are designed to offer emotional support and education throughout your cancer journey. Under professional guidance, patients and family members can discuss their anxieties and concerns with others who share a similar experience. This sharing opportunity facilitates improved communication and enhances everyone's ability to cope with their cancer diagnosis. To find a family support group in your area, go to www.lls.org/ia and select "Patient Support Programs".

LLS Community

Join a community of people who understand what you're going through. LLS Community is a place for you to connect with others affected by blood cancers and share your voice to drive change. The resources on LLS community are accurate, up-to-date, and from a trusted source. LLS Community relies on your experiences and insights to drive program development and research studies that address the needs and real-world challenges of patients living with blood cancer. To learn more or join, please visit communityview.lls.org.

Online Chats

Our live, weekly online chats provide a friendly forum to share experiences and chat with others about anything from the initial phase of diagnosis to treatment and survivorship. Each chat is moderated by an oncology social worker. The role of the moderator is to provide support and guide conversation, as needed, throughout the chats. Please visit: www.lls.org/support/online-chats

Educational Programs

The Leukemia & Lymphoma Society (LLS) sponsors many free live and archived teleconferences, podcasts, webcasts and more that you can view at your convenience. In addition, LLS sponsors a number of free community-based professional education programs for healthcare professionals, particularly for oncology nurses and social workers. Patients, their families and caregivers are also invited to attend. For a complete list of our programs see our National Patient Education Programs web page, www.lls.org/webcasts.

Advocacy Network

The chapter has an active network of volunteers who work with legislators to obtain access to quality medical treatment and legal protection in the health insurance and employment arenas. Involvement in shaping public healthcare policies is possible through the Advocacy Network. Register at <http://action.lls.org>.

Honored Hero Program

Our honored heroes provide inspiration and support for the LLS fundraising programs and are symbols of strength for others dealing with challenges in their lives. An honored hero is anyone who is being treated for, or is a survivor of, leukemia, lymphoma or myeloma. You can participate on several levels, including sharing your story, creating artwork, writing letters or attending fundraising events.

Throughout your diagnoses and treatment, you will have many options of care. Your healthcare team can help with any question you have and can provide referrals for information and resources. One of the goals of helping you “be your own advocate” is to provide you with a list of reputable organizations dedicated to servicing the needs of cancer patients and their families.

The Leukemia & Lymphoma Society (LLS) is pleased to provide you with the following list of resources that, in our opinion, represent some of the best local and national resources. Please call the Iowa Chapter at (515) 270-6169 for additional information about these resources.

LLS Sponsored Support Groups

Blood Cancer Support Group
John Stoddard Cancer Center
1221 Pleasant St
Des Moines, IA 50309
(515) 241-8505

Website: <http://www.johnstoddardcancer.org>

Secondary Website: <http://www.johnstoddardcancer.org>

For adult patients with leukemia, lymphoma, Hodgkin's disease, myeloma, or myelodysplastic syndromes and their family and friends. Support Group Time: 2nd Thurs of each month at 5:Yes5 pm. Location: Suite 45No of the John Stoddard Cancer Center

Iowa City: Meetings held first Wednesday evening (6:00 pm) of every February, May, August, and November at ACS Hope Lodge, 750 Hawkins Drive.

Please RSVP to Tammy Temple, LMSW at tammy-temple@uiowa.edu

Leukemia & Lymphoma Society Telephone Support Group
IA (515) 270-6169

Toll Free: (800) 347-1074

Website: www.lls.org

Secondary Website: www.lls.org

Date: 2nd Tuesday morning Please contact Wendy Sontag at

Yes-8NoNo-347-YesNo74 about times and locations.

Local Resources

Make-A-Wish® Iowa
3009 100th Street
Urbandale, IA 50322-3220
(515) 334-2636
Toll Free Iowa Only (800) 797-9474

Blood Sweat & Beers Iowa
3512 Ingersoll Avenue
Des Moines, IA 50312
E-mail: Tim.Mauro@BSBIowa.com

American Cancer Society - Des Moines
1717 Ingersoll Ave, Ste 111 ,
Des Moines, IA 50309
515-253-0147

American Cancer Society - Cedar Rapids
4080 First Ave NE Ste #101 ,
Cedar Rapids, IA 52402
319-365-5241

Tori's Angels
4677 Panorama Drive, Panora, IA 50216
712-249-6423
bridgley@netins.net

Pinky Swear
PO Box 1783
Des Moines, IA 50305
mary.core@pinkyswear.org
515-210-7148

Children's Cancer Connection
2708 Grand Avenue
Des Moines, IA 50312-5214
515.243.6239
Toll Free: Toll Free: 877.535.7802

Blood Cancer Organizations

In addition to the blood cancer services offered by The Leukemia & Lymphoma Society, organizations exist that focus on your specific disease. We encourage you to contact these diagnoses specific organizations. They may be able to provide additional support services such as educational materials, diagnoses specific resources and financial assistance programs.

BMT Information Network

2310 Skokie Valley Road, Suite 104
Highland Park, IL 60035
(847) 433-3313
www.bmtinfonet.org

Delete Blood Cancer

Online/National
New York, NY
www.deletebloodcancer.org/en

Lymphoma Research Foundation

The Lymphoma Research Foundation
Wall Street Plaza
88 Pine Street, Suite 2400
New York, NY 10005
212-349-2910
LRF@lymphoma.org

Centers for Medicare & Medicaid Services

7500 Security Boulevard Baltimore, MD 21244
(800) MEDICARE
www.medicare.gov

The Leukemia Research Foundation

3520 Lake Avenue, Suite 202
Wilmette, IL 60091
(847) 424-0600
www.leukemia-research.org

Multiple Myeloma Research Foundation

383 Main Avenue, 5th Floor
Norwalk, CT 06851
(203) 229-0464
www.themmr.org

The Myelodysplastic Syndromes Foundation

4573 S. Broad Street, Suite 150
Yardville, NJ 08620
(800) MDS-0839
www.mds-foundation.org

Resources | Pediatric & Young Adult Resources

American Childhood Cancer Organization

PO Box 498
Kensington, MD 20895
(855) 858-2226
www.acco.org

Children's Cancer Recovery Foundation

PO Box 238
Hershey, PA 17033
(800) 238-6479
www.childrenscancerrecovery.org

**Group Loop (Teens) Online/
National**

1050 17th Street, Suite 500
Washington, DC 20036
(888) 793-9355
<http://grouploop.org/>

**I'm Too Young for This
Cancer Foundation**

40 Worth Street, Suite 808
New York, NY 10013
(877) 735-4673
www.i2y.org

Kids Connected

(800) 899-2866
www.kidsconnected.org

**LiveStrong Lance Armstrong
Foundation**

2201 E. Sixth Street
Austin, TX 78702
(877) 236-8820
www.livestrong.org

Ulman Cancer Fund

6310 Stevens Forest Road
Columbia, MD 21045
(888) 393-3863
www.ulmanfund.org

**UnitedHealthcare Children's
Foundation**

PO Box 41, MN012-S286
Minneapolis, MN 55440-0041
(800) 328-5979
www.uhccf.org

Cancer Really Sucks

www.cancerreallysucks.org

**The Children's Leukemia
Research Association**

585 Stewart Avenue, Suite 18
Garden City, NY 11530
(516) 222-1944
www.childrensleukemia.org

Chemo Angels

Online www.chemoangels.net

First Descents

100 Arapahoe Avenue, Suite 8
Boulder, CO 80302
(303) 945-2490
www.firstdescents.org

**Foundation for Children with
Cancer**

11327 Gravois Road, Suite
202 St. Louis, MO 63126 (866)
800-8860
www.childrenwithcancer.org

Cancer Legal Resource Center

227 W. Monroe Street, 44th Floor
Chicago, IL 60606
(866) 843-2572
www.cancerlegalresourcecenter.org

Care Pages

345 Hudson Street, 16th Floor New
York, NY 10014
(646) 728-9500
www.carepages.com

Caring Bridge

1715 Yankee Doodle Road, Suite 301
Eagan, MN 55121
(651) 452-7940
www.caringbridge.org

SeventyK

www.seventyk.org

Stupid Cancer

40 Worth Street, Suite 808

New York, NY 10013

(877) 735-4673

www.stupidcancer.com

Teens Living with Cancer

www.teenslivingwithcancer.org

True North Treks

(773) 972-2367

www.truenorthtreks.org

Twist Out Cancer

www.twistoutcancer.org

Who Cares:**Teen Cancer America**

www.teencanceramerica.org

National Marrow**Donor Program****Be The Match**

3001 Broadway Street N.E.

Minneapolis, MN 55413

(888) 999-6743

www.bethematch.org

National Patient**Travel Center**

4620 Haygood Road, Suite 1

Virginia Beach, IL 23455

(800) 296-1217

www.patienttravel.org

Bone Marrow Foundation

30 East End Avenue, Suite 1F

New York, NY 10028

(800) 365-1336

www.bonemarrow.org

Brenda Mehling**Cancer Fund**

24152 Lyons Avenue, Suite 157

Santa Clarita, CA 91321

(661) 310-7940

www.bmcf.net

**Critical Mass Young Adult
Cancer Alliance**

2201 E. Sixth Street

Austin, TX 78702

(877) 236-8820

<http://criticalmass.org>

FertileHOPE

2201 E. Sixth Street

Austin, TX 78702 855.220.7777

<http://www.fertilehope.org/>

I Had Cancer

www.ihadcancer.com

The SAM Fund

89 South Street, Suite LL02

Boston, MA 02111

(617) 938-3484

www.thesamfund.org

**The National Children's
cancer Society (NCCS)**

500 North Broadway, Suite 1850

St. Louis, MO 63102

(341) 241-1600

<http://www.thenccs.org/>

Cancer and Careers

Online/National
New York, NY
www.cancerandcareers.org/en

Catholic Charities

721 N LaSalle Street
Chicago, IL 60625
(312) 655-7700
www.catholiccharities.net

CancerCare

275 Seventh Avenue
New York, NY 10001
(800) 813-4673
www.cancercare.org

Chronic Disease Fund

6900 N. Dallas Parkway, Suite 200
Plano, TX 75024
(877) 968-7233
www.gooddaysfromcdf.org

Gracious Gifts

Online
(312) 636-7554
<https://www.facebook.com/graciousgiftsnonprofit/info>

Patient Advocate Foundation

421 Butler Farm Road
Hampton, VA 23666
(800) 532-5274
www.patientadvocate.org

Wooden Nickels

PO Box 5287
Evanston, IL 60204
(888) 842-2654
www.nowoodennickels.org

Patient Access Network Foundation

PO Box 221858
Charlotte, NC 28222
(866) 316-7263
www.panfoundation.org

Association of Cancer Online

Resources
New York, NY
www.acor.org

Cleaning For A Reason

211 S. Stemmons, Suite G
Lewisville, TX 75067
(877) 337-3348
www.cleaningforareason.org

Lotsa Helping Hands

34 Washington Street, Suite 310
Wellesley Hills, MA 02481
www.lotsahelpinghands.com

National Coalition for Cancer Survivorship

1010 Wayne Avenue, Suite 770
Silver Spring, MD 20910 (877)
NCCS-YES
www.canceradvocacy.org

