

Dear Family,

On behalf of the Board and staff at Children's Leukemia Foundation of Michigan (CLF), I would like you to know that your family is in our thoughts. We understand how overwhelming it is to be told that you or your loved one is facing a serious illness. After the initial shock wears off, you have many questions and you need answers.

That's why we created *Stepping Stones*. Available to each family that registers with CLF, *Stepping Stones* is a resource kit filled with information that will help patients and caregivers cope with the realities of life with leukemia, lymphoma and other malignant or potentially malignant blood disorders.

First, *Stepping Stones* will guide you through the services CLF has to offer. We're dedicated to helping families like yours with information, financial assistance and emotional support. Section 1 describes all of our programs and how to use them. And the Confirmation of Enrollment form in the front of the packet shows you the specific financial assistance programs for which your family may be eligible.

Next, this resource kit will walk you through some of the most common issues of concern for families facing cancer and pre-cancer – issues like understanding the diagnosis and treatment, coping with side effects, working with the health care team, and dealing with emotional and financial strains. *Stepping Stones* is not intended to substitute for advice from your health care team. Rather, it's meant to provide you with facts, interactive exercises and referrals that will enhance your overall awareness.

At CLF, we strongly believe that knowledge is power. That phrase is used often, but it's so true. As its name suggests, *Stepping Stones* is meant to be a base from which you will continue to learn. As you progress through the initial diagnosis to various stages of treatment and recovery, *Stepping Stones* will arm you with some basic, solid information. Through your own personal investigation and experiences, you'll continue to expand your knowledge. *Stepping Stones* is presented in a packet format so that you can add new, valuable information as it becomes available. In a way, you can think of this resource kit as your "home base" – the place to which you can return when you need information that can help you cope. We hope it will help you become empowered and informed.

As you face good times and bad, please remember that Children's Leukemia Foundation of Michigan is here for you. We hope you will find *Stepping Stones* and our other programs and services valuable. We'll be contacting you soon, just to touch base and see how things are going. Please don't hesitate to give us a call or drop us an e-mail if we can be of any assistance in the meantime. We wish you and your family the best.

Sincerely,



Melissa Antonic, LMSW, ACSW
Director of Patient Services



TAB NAME: "OVERVIEW"

Welcome to CLF

Your family is officially registered with Children's Leukemia Foundation of Michigan (CLF). This means we have received your completed Patient Information Form, your status has been activated in our patient database, and your family is now eligible to receive our free services. Welcome.

Children's Leukemia Foundation of Michigan was founded in Detroit in 1952 by a group of parents who had each suffered the loss of a child due to leukemia. Together, this group resolved to support other families affected by this devastating illness.

As time went on, CLF's reach expanded. Today, CLF serves the entire state of Michigan, and we provide services for both children and adults. In addition, we now cover any malignant or potentially malignant disorder of the blood, bone marrow or lymphatic system. This includes leukemia, Hodgkin's disease, non-Hodgkin's lymphoma, multiple myeloma, aplastic anemia, myelodysplastic syndromes and more. Please refer to Section 2 for descriptions of covered diseases.

It has always been CLF's mission to provide compassionate, personalized support to families facing these serious illnesses. Please read on to learn about information, financial assistance and emotional support we can offer your family. We are here to help, and encourage you to take advantage of these free services.

Information

Casework, Information & Referral

When you call 800.825.2536, CLF's toll-free telephone number, you will be connected with an open ear, friendly voice and steady hand. In other words, you'll be linked with one of our Patient Services Coordinators (PSCs). These staff members are professionally educated and trained to determine your needs and lend support during difficult times.

Our Patient Services Coordinators listen to your questions and concerns and do their best to guide you to appropriate solutions. Many times, walking you through CLF's programs, policies and procedures is part of the solution. But the job doesn't end there. Our Patient Services Coordinators are constantly learning about what other organizations have to offer so they can make appropriate referrals to meet your needs. CLF's goal is to empower you with as many resources as possible.

As you'll see from the letter in the front of this resource kit, one of our Patient Services Coordinators has been specifically assigned to your family. Your PSC will contact you from time to time to ask you how things are going and to see if we can be of any assistance. Your Patient Services Coordinator will also be the contact person you ask for whenever you call CLF with a question. We assign a specific person to you simply to give you a sense of consistency – something that families have stated they have found valuable in the past. Please be assured, however, that if your contact person is not available when you call, another Patient Services Coordinator will be capable and happy to assist you with your needs.

Our Patient Services Coordinators are available during normal office hours (8:30 AM to 4:30 PM). If you call when the office is closed, the voice mail system will allow you to leave a detailed message, and your call will be returned promptly when the office re-opens. Please don't hesitate to call. We'll always do our best to help.

Resources

We are able to provide your loved ones with access to a wide variety of print, audio, video and electronic information that can help you learn more about the patient's diagnosis, treatment options and other related issues.

CLF acts as a clearinghouse for educational brochures and booklets from leading cancer and health authorities. If you've already spoken to one of our Patient Services Coordinators, you may have already been provided with copies of materials you may have found useful. A complete listing of the brochures we carry can be found in the back of this packet.

We understand that people can take a variety of actions to learn. That's why we let people sign out books, videos, and audio materials. A complete listing of these materials is also included in the back of this packet.

Resources are available to any Michigan resident. To request materials, simply call, fax or e-mail us with your request. We can mail you up to five brochures at a time, and these materials are yours to keep. Books, audio, and video materials are available for loan. You can borrow up to two items at a time for a two-week loan period. We'll ship materials to you free of charge, and we'll even provide you with a postage-paid envelope for their return.

We encourage you and your loved ones to take advantage of this opportunity to learn. As always, knowledge is power, and we're here to help.

Financial Assistance

Traditional Financial Assistance Program

Because your family has registered with us, you may be eligible to receive financial assistance in the form of reimbursements from CLF. Every July 1, the availability of funds is determined for our fiscal year. While our assistance may only be a drop in the bucket of overwhelming health care costs, we know that every little bit helps. CLF is proud to be one of the few organizations that is able to provide direct financial assistance.

Your Confirmation of Enrollment form (in the front of this packet) will explain the expenses for which you are eligible to receive reimbursement. This determination is based on your health insurance coverage, as well as other factors.

Depending on your eligibility and the availability of funds, you may be able to be reimbursed for the following expenses:

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- **Treatment costs*** – Patients with no health insurance coverage for treatment costs and patients with Medicaid can be reimbursed for doctor’s visits, lab tests, hospital stays and other treatment-related expenses. To be reimbursed, please submit copies of your treatment statements and your receipts or cancelled checks to show that you have paid for the expenses.
 - **Prescription costs*** – Patients with no health insurance coverage for prescriptions and patients with Medicaid can be reimbursed for medications necessary to treat the patient’s cancer/pre-cancer. To be reimbursed, please submit copies of your pharmacy/ prescription statements and your cash register receipts or cancelled checks to show you have paid for the expenses.
 - **Travel costs** – All families are eligible to be reimbursed for the patient’s travel to and from treatment. (This does not include the family’s travel to visit the patient in the hospital.) If the patient is receiving an allogeneic bone marrow/stem cell transplant, CLF can also provide reimbursement for the donor’s transplant-related travel. For automobile travel, CLF reimburses \$0.15 per mile. Please complete a CLF Travel Form (see the front section of this packet) with your round-trip mileage, and attach documentation from the treatment center to prove the patient was seen on the dates listed. For bus, train or plane travel, please submit a receipt to show you have paid for the ticket, and documentation from the treatment center to verify the patient was seen between the dates of travel. CLF is also able to reimburse for treatment center parking expenses (for the patient only). To be reimbursed, please submit paid receipts from the parking lot/ structure, and documentation to show the patient was seen on the dates listed.
 - **Wigs/head coverings** – All patients are eligible to be reimbursed for the cost of wigs, prosthetic hair pieces, turbans, scarves, hats or other head coverings designed to help people cope with treatment-related hair loss. To be considered for reimbursement, please submit your paid receipts or cancelled checks.

** If you have health insurance, but learn that a specific procedure or medication prescribed by the oncologist is not covered, CLF may be able to provide reimbursement. You must provide CLF with a confirmation letter from the physician, and a copy of your paid receipt. Please contact your Patient Services Coordinator to discuss your specific situation.*

CLF is unable to provide reimbursement for health insurance deductibles, health insurance co-pays, and treatment, medication, or travel for conditions not related to the patient’s malignant or potentially malignant blood disorder.

Receipts, forms and supporting documentation should be submitted to CLF on a monthly basis. Normally, your reimbursement check will be mailed one week after we receive these materials. Expenses incurred before the first contact date listed on your Confirmation of Enrollment form cannot be honored. Requests submitted more than one year after the expense was incurred cannot be honored. Please contact the Patient Services department with any questions or concerns.

Special Needs Fund

There are many costs that fall through the cracks of traditional financial aid programs. CLF's Special Needs Fund was created as a one-time grant to help with these expenses.

Separate from the reimbursement fund mentioned earlier, CLF's Special Needs Fund is designed to help patients and family members who, after a thorough investigation of other resources, are unable to meet expenses that are causing a financial burden. Expenses addressed by CLF's Special Needs Fund generally fit into three categories:

1. **Expenses that must be paid in order for the patient to get needed treatments** – Examples include family lodging for out-of-town treatment, post-BMT lodging, car repairs and COBRA payments.
2. **Emergency payments to help the patient/family cover non-negotiable, basic needs and avoid further financial penalties** – Examples include rent/mortgage payments, car payments or car insurance, child care and utility shut-off notices.
3. **Expenses that are unexpected, but necessary because of diagnosis or treatment, related side effects, or because of the patient's general health condition** – Examples include medical equipment or specialized furniture, sperm banking and medically necessary home improvements/repairs.

If you're having a hard time meeting a specific expense, contact your Patient Services Coordinator to discuss the Special Needs Fund. You will need to complete an application and provide supporting documentation (e.g. copies of invoices or payment book pages, written estimates, collection or shut-off notices) to verify the amount of the request.

CLF's Special Needs Fund is limited and, unfortunately, CLF is not able to fulfill every request. CLF attempts to meet as many needs as possible. Some applications may be approved for lower than the requested amount, while others may not be granted. If you are not granted funding, you may reapply to the Special Needs Fund after six months.

Emotional Support

Peer Support Network

While the support of friends, family and your health care team is very important, there's something special about support that comes from others who have "been there." CLF's Peer Support Network links newly diagnosed patients and family members with peer volunteers who share common experiences.

If you believe this type of support would be helpful, simply contact your Patient Services Coordinator. Your PSC will take some basic information from you like age, marital status, number of children, diagnosis, treatment and general concerns, in order to match you with an appropriate Peer Support Network volunteer. CLF will then contact the peer volunteer and provide them with background information about you and your concerns. At a mutually convenient time, the Peer Support Network volunteer will give you a call so you can discuss the issues on your mind.

Many people who are connected through the Peer Support Network stay in contact for months or years. It's so helpful to have a "buddy" who can relate to your feelings and concerns on an exceptional level.

Internet/Web Services

Patients and family members are offered a variety of opportunities to gain peer support. Please go to CLF's website (www.leukemiamichigan.org) to learn about all the peer support programs that CLF is offering.

Whether you are interested in gaining support from the comfort of your own home or would prefer a traditional, walk-in support group, CLF's website has the resources and information you are looking for.

Visit our website regularly for updated information on the services being offered.

Recreational Events

When you're facing the stresses of a serious illness, you often wish you had the chance to "escape," even if only for a few hours. Unfortunately, when medical issues stretch your time and finances, recreation opportunities are often the first thing to get cut from a family's schedule and budget.

CLF hosts a variety of fun-filled, free recreational events in order to give families a chance to relax without the stress of having to make a lot of plans or do any budgeting. Recent family events have included dinner-and-a-movie nights, days at the zoo, bowling parties, evening cruises, nights at the theater, miniature golf and arcade outings, and paint your own pottery events. We try to host excursions throughout the state, so we'll be sure to contact your family for our next event in your area.

This is a great opportunity to take a break and let someone else worry about the details and the cost. The extra added benefit is that you'll be able to interact with families who are facing similar circumstances. It's great to know that you're not alone.

Interactive Workshops

CLF collaborates with other organizations, and works with specialists in a variety of fields, to bring interactive workshops to families. Leaders make presentations on specific issues (e.g. fatigue, humor and healing, creative expression and nutrition), and then allow ample time for questions and story sharing. This offers participants a chance to gain knowledge and support not only from professionals, but also from their peers – both have a unique expertise to offer.

We'll contact you by email to announce upcoming workshops in your area.

Holiday Toys & Holiday Open Houses

CLF understands that living with a serious illness can put a significant strain on a family's time, finances and emotions – especially during the December holidays. Through our Holiday Toys program, CLF aims not only to lift families' spirits, but also to provide some stress relief.

CLF's Holiday Toys program provides gift packages to child patients and their siblings, and to the children of adult patients. Children, ranging in age from infancy to 18 years of age, are eligible to receive gifts.

In mid-October, we'll send your family a Holiday Toys registration form. If your children are 18 or under, we'll ask you to list each child's name, age, gender and interests. This way, we can do our best to match them with suitable gifts. Each child receives 3-4 new gifts.

Gift packages are shipped free of charge, or your family can pick them up at CLF's office in Farmington Hills or at one of our Holiday Open House events. They are generally ready at the end of November or in early December. We hope they'll make the holidays a bit brighter for you and your loved ones.

In addition, each year CLF hosts Holiday Open House events in one or more Michigan locations where families can not only pick up their Holiday Toy packages, but can enjoy a day of food, crafts and a visit with Santa.

Tickets Program

As mentioned earlier, sometimes you just need a break. Through the generosity of our donors, CLF is often able to send families to local entertainment venues like sporting events, music concerts, theater performances or festivals to provide some temporary but needed respite from the demands of living with a serious illness.

When tickets are available in your area, a Patient Services Coordinator will contact you by email, mail or phone to see if your family is interested in attending the event.

You Should Also Know...

Research & Special Projects

In addition to providing programs and services that directly benefit patients and their families, CLF does its share to support undertakings that affect the leukemia/lymphoma community as a whole.

CLF provides research funding to Michigan's two National Cancer Institute designated Comprehensive Cancer Centers: Barbara Ann Karmanos Cancer Institute and University of Michigan Comprehensive Cancer Center. Since CLF was founded, the agency has granted more than \$6.5 million to support leukemia/lymphoma research.

CLF also provides grants of up to \$2,500 to health professionals for special projects and professional development that impacts their work with people facing these diseases. This funding has helped support small studies and research projects, a new caregiving program, the acquisition of patient education materials, patient workshops, community events and more.

CLF will keep you posted with changes to existing services and the development of new programs. Please don't hesitate to contact us at 800.825.2536 or info@leukemiamichigan.org with any questions or concerns. Remember, we're here to help. We look forward to working with you.

TAB NAME: "DIAGNOSIS"

Diagnosis & Treatment Basics

This section provides a brief summary of the different types of malignant (cancerous) and potentially malignant (pre-cancerous) disorders of the blood, bone marrow and lymphatic system. It also discusses the treatment options available for people facing these illnesses.

This is simply an overview. In the back pocket of this binder, you will find lists describing the brochures, books, video and audio materials found in CLF's Resource Room. Many of these educational materials discuss diagnosis and treatment issues in greater detail. CLF encourages you to take advantage of this free service. Come visit CLF's Resource Room in person, or call, fax, mail or e-mail us your request.

In addition, Section 8 of this binder lists organizations that can provide you with more information. You may also contact CLF's Patient Services department for further assistance.

CLF reminds you that this information is not intended to substitute for advice from your health care team. It is provided to empower you to become an informed patient or caregiver.

Blood, Marrow & Lymphatic System

A basic understanding of the blood, bone marrow and lymphatic system will help you better understand the diagnoses that CLF addresses.

Blood Cells

Blood consists of a liquid called plasma and three types of cells:

- **White blood cells** – These cells help the body fight infection and disease. If normal production of white blood cells is blocked, the body becomes more susceptible to illness and infection.
- **Red blood cells** – The majority of blood cells are red blood cells. These cells carry oxygen from the lungs to tissues throughout the body. They also carry carbon dioxide from the tissues back to the lungs to be exhaled. Red blood cells contain an iron-rich protein called hemoglobin, which gives blood its red color. If normal production of red blood cells is blocked, not enough oxygen gets to the body's tissues, and a person experiences anemia. Symptoms of anemia include weakness, headaches, lack of energy, paleness and shortness of breath.
- **Platelets** – These cells help blood clot and control bleeding. If normal production of platelets is blocked, the body bleeds and bruises easily.

Bone Marrow

Bone marrow is the soft, spongy substance in the center of bones. This is where blood cells are produced by stem cells.

Lymphatic System

The lymphatic system provides the body's defense against infection and disease. It consists of the tissues and organs (including the bone marrow, lymph nodes, thymus, spleen, tonsils, adenoids and appendix) that produce and store infection-fighting white blood cells, and the network of vessels that carry lymph (a watery, colorless fluid that contains white blood cells called lymphocytes) throughout the body.

Diagnoses

Cancer in General

Cancer is a term that describes a group of more than 100 diseases – the common thread being the growth of abnormal cells. Affected cells divide without control and eventually crowd out healthy cells.

In most cases, it's not completely known what causes cancer. Scientists and doctors believe that genetics, environment, lifestyle, or a combination of these factors can contribute to a cancer diagnosis, but there is no single determining factor. What we do know is that cancer is not contagious (you can't "catch" it from another person), and you can't get it from a physical injury. In addition, we know that cancer does not discriminate based on gender, age, race, religion, sexual orientation, socio-economic status or the perceived "goodness" of a person. Cancer affects people from all walks of life.

The medical community has been studying cancer and its effects for many years. While we can't yet prevent cancer from ever occurring, or guarantee that the disease will be eliminated if it does occur, medical research has helped us discover new and more effective ways to treat cancer. Additionally, psychosocial research has helped us understand how to better cope with this illness.

Leukemia

Leukemia is cancer of the blood cells. Abnormal white blood cells overpopulate the bone marrow and spill into the bloodstream, blocking production of normal white blood cells, red blood cells and platelets. Each year, approximately 1,440 new cases of leukemia are diagnosed in Michigan (about 60,000 new cases per year in the U.S.). Symptoms of leukemia include frequent infections, fever, weakness, exhaustion, flu-like symptoms, easy bleeding and bruising, unexplained loss of appetite or weight, swollen lymph nodes, and an enlarged liver or spleen.

Leukemia is classified in two ways – by the type of white blood cell affected, and by how quickly the disease progresses. If the leukemia affects white blood cells called lymphocytes, it is called lymphocytic leukemia. Lymphocytic leukemia is also sometimes called lymphatic, lymphogenous or lymphoblastic leukemia. If the leukemia affects white blood cells called granulocytes (a.k.a. myeloid cells), it is called myelogenous leukemia. Myelogenous leukemia is also sometimes called myelocytic, myeloblastic, granulocytic, nonlymphocytic or nonlymphoblastic leukemia.

Leukemia is labeled “acute” when it affects immature blood cells and progresses quickly. It is labeled “chronic” when it affects more mature blood cells and progresses slowly.

Thus, there are four main types of leukemia:

- **Acute lymphocytic leukemia (ALL)** – ALL is the leading form of leukemia in children, but it also affects adults (especially those over age 65).
- **Acute myelogenous leukemia (AML)** – AML is the most common form of acute leukemia in adults. It’s usually found in people over age 50, but can affect all ages. It’s also more common in men than women.
- **Chronic lymphocytic leukemia (CLL)** – CLL is considered a disease of middle aged or older adults. 90 percent of CLL patients are over age 50 at the time of diagnosis. It also affects more men than women. CLL is the most common of all the leukemias in Western countries.
- **Chronic myelogenous leukemia (CML)** – CML usually affects adults between the ages of 30 and 50, but it can affect all ages. Most people who have CML have something called “Philadelphia chromosome” which is a translocation of genetic information between one of the chromosomes in pair 9 and one in pair 22.

Hairy cell leukemia is a rare form of chronic lymphocytic leukemia. It gets its name because the affected lymphocytes have short, thin projections that resemble hairs when viewed under a microscope.

Lymphoma

Lymphoma is cancer that starts in the tissues of the lymphatic system. Cells grow abnormally, divide too rapidly, and spread from one part of the system to the next. They can form tumors and can spread to other organs in the body, like the lungs and liver. As the disease progresses, the body becomes less able to fight infection. Symptoms include painless swelling in the lymph nodes, neck, underarm, or groin, fever, fatigue, night sweats, weight loss, itching skin and an enlarged spleen.

There are two distinct types of lymphoma – Hodgkin’s disease and non-Hodgkin’s lymphoma:

- **Hodgkin’s disease** – Hodgkin’s disease is the most common type of lymphoma, and is distinguished from other forms of the disease by the consistent presence of Reed-Sternberg cells in the lymph nodes. Reed-Sternberg cells are cells with particular characteristics, and are named for the scientists who discovered them.

Hodgkin's disease also has a predictable pattern of spread. Each year, approximately 283 people in Michigan are newly diagnosed with Hodgkin's disease (about 8,500 new cases each year in the U.S.). It most often affects people between the ages of 15 and 34, but can affect people of all ages. More men than women are affected.

- **Non-Hodgkin's lymphoma** – Non-Hodgkin's lymphoma refers to a group of lymphomas that progress in a less predictable and systematic way than Hodgkin's disease. These lymphomas cannot be distinguished by the presence of one particular type of cell. There are approximately 30 different types of non-Hodgkin's lymphoma. They are usually classified based on how slowly or rapidly the disease progresses. Slow growing lymphomas (e.g. cutaneous T-cell lymphoma) are referred to as "indolent," while fast growing lymphomas (e.g. Burkitt's lymphoma) are labeled "aggressive." Approximately 2,249 new cases of non-Hodgkin's lymphoma are diagnosed in Michigan each year (72,500 new cases each year in the U.S.). Over 95 percent of cases occur in adults, with the average age at diagnosis being in the early 40s.

Once lymphoma is diagnosed, further testing is done to determine the stage (the extent/spread) of the disease.

- **Stage I** – The disease is found in one lymph node area, or in one organ/area outside the lymph nodes.
- **Stage II** – The disease is found in two or more lymph node areas that are on the same side of the diaphragm (e.g. in the neck and in the chest).
- **Stage III** – Several lymph node regions are involved (on both sides of the diaphragm).
- **Stage IV** – The disease involves many lymph nodes and organs outside of the lymphatic system (e.g. the lungs or liver).

The stage may be followed by the letter B (if a specific symptom like fever above 100°, night sweats, or loss of 10 percent or more of normal body weight is present) or by the letter A (if no specific symptoms are present).

To determine the prognosis and treatment course, a physician will consider the stage of the disease, the presence of B symptoms, and the presence of bulky disease or large mediastinal masses.

Multiple Myeloma

Multiple myeloma is cancer of the plasma cells (large, antibody-producing white blood cells). As abnormal plasma cells are produced, they collect in the bone marrow and in the hard, outer part of bones. These cells can form a single tumor (called a plasmacytoma), but most often they form multiple tumors. They also produce chemicals that weaken and erode bones, causing pain. When bones are damaged, calcium is released into the bloodstream. This can lead to hypercalcemia (too much calcium in the blood). Symptoms include muscle weakness, loss of appetite, nausea, thirst, fatigue, restlessness and confusion.

The abnormal plasma cells also secrete excess antibodies that prevent the kidneys from cleaning the blood properly. As the disease progresses, it becomes difficult for the marrow to produce normal blood cells.

Multiple myeloma is also known as myeloma, plasma cell myeloma, myelomatosis and plasma cell dyscrasia. Symptoms include bone pain (most often in the back or ribs), broken bones, weakness, fatigue, weight loss and repeated infections. Each year, about 710 new cases of multiple myeloma are diagnosed in Michigan (about 30,000 new cases per year in the U.S.). Eighty percent of cases occur after the age of 60 (it rarely occurs in people under the age of 40). There is a slightly higher incidence of multiple myeloma in African-Americans.

Aplastic Anemia

Aplastic anemia is a rare disease in which the production of blood cells slows or stops. This is known as bone marrow failure. Blood levels of red cells, white cells and platelets thus decrease to dangerous levels. Approximately 25-35 new cases of aplastic anemia are diagnosed each year in Michigan (about 300-600 new cases per year in the U.S.). Symptoms of this condition include tiredness, easy bleeding and bruising, and frequent infections.

Aplastic anemia is potentially malignant (cancerous) and most often affects people between the ages of 15 and 24 or over the age of 60.

Myelodysplastic Syndromes

Myelodysplastic syndromes (MDS) occur when blood cells lose their ability to mature. As these immature blood cells (known as blasts) take over the bone marrow, they prevent it from making enough normal white cells, red cells and platelets. In addition, the existing mature blood cells may not function properly. Each year, approximately 465 new cases of MDS are diagnosed in Michigan (about 13,000 new cases per year in the U.S.). Symptoms of MDS include fatigue, shortness of breath, weakness, frequent infections, easy bruising and bleeding, and enlarged lymph glands or an enlarged spleen.

MDS is also known as myelodysplasia, dysmyelopoiesis, oligoblastic leukemia, smoldering leukemia and preleukemia. As some of these names suggest, myelodysplastic syndrome is potentially malignant (cancerous). In fact, up to one-third of MDS cases will progress to a form of leukemia (usually acute myelogenous leukemia or AML). MDS most often affects people over the age of 60, but it can affect all ages. It usually affects more men than women.

Myelodysplastic syndromes are categorized by how affected cells look under a microscope, and by the number of blasts found in the bone marrow. There are five types of MDS:

- **Refractory anemia (RA)** – RA primarily affects red blood cells. Less than 5 percent of the cells in the marrow are blasts.

- **Refractory anemia with ringed sideroblasts (RAS)** – In RAS, the red blood cells are unable to process the iron that normally goes into hemoglobin. It is instead deposited inside the red blood cells, forming a distinctive ring that can be seen when viewed through a microscope. Less than 15 percent of the cells in the marrow are blasts.
- **Refractory anemia with excess blasts (RAEB)** – RAEB mainly affects the white blood cells. 5 to 20 percent of the cells in the marrow are blasts.
- **Refractory anemia with excess blasts in transformation (RAEB-t)** – RAEB-t mainly affects the white blood cells. 21 to 30 of the cells in the marrow are blasts, which indicates that this condition could transform into acute myelogenous leukemia (AML)
- **Chronic myelomonocytic leukemia (CMML)** – CMML affects white blood cells called monocytes. 5 to 20 percent of the cells in the marrow are blasts

Myeloproliferative Disorders

Myeloproliferative disorders are diseases in which the bone marrow produces too many of certain types of blood cells. They are considered to be potentially malignant (cancerous). There are four types of myeloproliferative disorders:

- **Polycythemia vera** – Polycythemia vera is a condition where too many red blood cells are produced, which results in increased blood volume and thickness. Symptoms include bleeding and clotting problems, headache, dizziness, vision problems, inability to concentrate and itching all over the body. The spleen may also swell because the extra blood cells collect there. This rare condition can affect all ages, but it's generally considered a disease of middle aged or older adults.
- **Essential thrombocythemia** – Essential thrombocythemia is a condition where the number of platelets in the blood is much higher than normal. These extra platelets make it difficult for blood to flow normally. Symptoms include bleeding and bruising problems, burning or numbness in the fingers or toes, itching/tingling skin, headache and fatigue.
- **Myelofibrosis** – Myelofibrosis (also known as agnogenic myeloid metaplasia) is a condition in which red blood cells and granulocytes (a type of white blood cell) do not mature properly. Red blood cells are teardrop-shaped (instead of disc-shaped). Symptoms include fatigue and weakness. The spleen and liver also start producing blood cells (to compensate for the problems in the bone marrow), so these organs may swell.
- **Chronic myelogenous leukemia** – See the description in the leukemia section.

Fanconi Anemia

Fanconi anemia (named for the pediatrician who first studied it) is a rare genetic condition. Both parents must be carriers of a recessive Fanconi anemia gene for their child to be born with this disorder.

Congenital disabilities (birth defects) are found in the majority of patients who have Fanconi anemia. These may include short stature, abnormalities of the thumbs or arms, skeletal malformations, kidney problems, skin discoloration, small head or eyes, mental retardation, low birth weight, heart defects, small reproductive organs, or gastrointestinal tract problems. These problems may range from minor to serious. A person may have one of these conditions, a combination of conditions, or none at all.

Ultimately, Fanconi anemia leads to aplastic anemia (bone marrow failure). The production of blood cells slows or stops, and blood levels of red cells, white cells and platelets decrease to dangerous levels. Symptoms of this condition include tiredness, easy bleeding and bruising, and frequent infections.

Waldenstrom's Macroglobulinemia

Waldenstrom's macroglobulinemia is a very rare, chronic (long lasting and slow progressing) cancer that affects the plasma cells (large, antibody-producing white blood cells). Abnormal plasma cells multiply out of control and invade the bone marrow, lymph nodes, and spleen. They also produce excessive amounts of an antibody called IgM. As this antibody builds up in the blood, it causes hyperviscosity (thickening of the blood). Each year, about 35 new cases of Waldenstrom's macroglobulinemia are diagnosed in Michigan (1,000-1,500 new cases per year in the U.S.).

Waldenstrom's macroglobulinemia may also be called hyperglobulinemic purpura, Waldenstrom's purpura, macroglobulinemia or Waldenstrom's syndrome. Symptoms include fatigue, headaches, weight loss, easy bleeding, visual problems, dizziness, confusion, loss of coordination, and enlarged lymph nodes or an enlarged spleen. However, a person may have this condition and be asymptomatic (have no symptoms). Waldenstrom's macroglobulinemia usually affects people over the age of 65, but it can occur in younger people. It is more common in men than women.

Diagnostic Techniques

There are a number of procedures that may be used to help a physician diagnose or determine the patient's particular condition.

Complete Blood Count (CBC)

Blood is taken from a fingertip or a vein, and tests are run to check the number of red blood cells, white blood cells and platelets. A CBC also measures the differential (the percentage of each of the different types of white blood cells), hematocrit (the percentage of red blood cells), and hemoglobin (the amount of oxygen-carrying protein).

Bone Marrow Aspiration

A long, hollow needle is inserted into the hip, rib or breast bone to remove a small amount of liquid bone marrow for microscopic exam.

Bone Marrow Biopsy

A bone marrow biopsy is similar to a bone marrow aspiration, but the needle is inserted deeper (usually into the hip bone) and removes a small piece of the bone along with the marrow.

Spinal Tap/Lumbar Puncture

As the patient lies in a curled position on his/her side, a needle is inserted between the vertebrae to remove a small amount of the fluid that bathes the brain and spinal cord. This fluid is then examined under a microscope to identify malignant cells. For patients with leukemia and lymphoma, chemotherapy is often injected directly into the spinal fluid after the sample is removed.

X-Ray

Short, high-energy electromagnetic waves penetrate the body and produce pictures that can be examined to determine which areas of the body are affected by disease. This helps identify tumors, masses, or an enlarged liver or spleen.

Magnetic Resonance Imaging (MRI)

Powerful electromagnets, radio frequency waves, and a computer work together to produce very detailed pictures of the body (including the cerebrospinal fluid and bone marrow), which are then examined to determine affected areas and the extent of the cancer spread.

Treatment

Chemotherapy

Chemotherapy is the use of drugs to treat cancer. Chemotherapy works to kill cancer cells, to keep them from reproducing, or to slow or stop their growth. There are currently more than 60 anti-cancer drugs that can be used alone or in combination. The type of cancer, the stage of the disease, the patient's overall medical condition, and the goal of treatment (cure, extended survival, or simple relief of symptoms/patient comfort) all play a role in determining the type and dose of chemotherapy that will be prescribed.

Chemotherapy can be given on an inpatient or outpatient basis or at a person's home. A person may receive chemotherapy in different ways:

- **Orally** – The drug is in pill, capsule or liquid form and is taken by mouth.
- **Intravenously** – The medicine goes directly into a vein. Drugs may be injected into a small vein on the hand or lower arm. Chemotherapy may also be given through a central venous catheter – a thin tube that is surgically placed into a large vein. This tube may be attached to a plastic or metal port that extends outside the body. The catheter and port remain in place as long as treatment is needed. Blood and medicine can enter or exit the port using a special needle.
- **Intramuscularly** – The drug is injected into the muscle (usually in the arm, thigh or buttocks).
- **Intrathecally** – During a spinal tap (see description in the Diagnostic Techniques section) medicine is injected directly into the spinal fluid.
- **Via implant** – The drug is made into a disc, which is surgically implanted near a tumor.

Side effects of chemotherapy vary depending on the person and the types of drugs used. Common side effects include nausea, vomiting, mouth sores, appetite loss, diarrhea, constipation, hair loss, fatigue and lowered blood counts (which causes increased infection, bruising and weakness).

Radiation Therapy

Radiation therapy is the use of high-energy particles or rays/waves to treat cancer. Radiation therapy kills cancer cells or keeps them from growing and spreading. It can be directed to a specific area, or to the whole body (total body irradiation). Radiation can be given:

- **Externally** – This method is used most often. Before the treatment course begins, a simulation takes place. This procedure uses computers and other tests to determine the exact spot where the rays or particles will be aimed, and the exact size and location of the area to be treated. The skin is marked with ink or dye to show this spot. When the treatment course begins, a machine (usually a linear accelerator) directs high-energy rays or particles at the predetermined area. Radiation may be directed to the same area on the body from different directions in order to reduce the chance of skin damage. The total dose of radiation and the number of treatments depends on

the type and stage of the patient's cancer, the overall medical condition, and other treatment being received. Radiation therapy is usually given on an outpatient basis.

- **Internally** – Internal radiation is also known as brachytherapy. A radioactive substance is sealed in an implant and placed in or near a tumor. These implants can be temporary or permanent. Radioactive sources may also be given orally (unsealed). Either may require a hospital stay to protect others from rays transmitted outside the body.

Side effects of radiation therapy vary depending on the person, the path of the radiation and the specific treatment course. Common side effects include fatigue, skin irritation, hair loss, mouth or throat sores, nausea and diarrhea.

Bone Marrow/Stem Cell Transplant

The main purpose of a bone marrow/stem cell transplant is to allow the patient to receive very high doses of chemotherapy or radiation in order to effectively destroy abnormal cancer cells. However, such large doses also severely damage healthy cells, including stem cells (the "mother cells" that produce red and white blood cells and platelets). Healthy stem cells must therefore be replaced/transplanted.

There are two types of transplant:

- **Autologous** – The healthy stem cells are harvested from the patient (before high dose chemo or radiation).
- **Allogeneic** – The healthy stem cells come from another person (either a related or unrelated donor) whose tissue type closely matches that of the patient. Unless the donor is an identical twin, there is a chance that the patient's body may reject the cells (this is known as graft vs. host disease), but measures are taken to try to minimize the related negative effects.

Stem cells can be found:

- **In the bone marrow** – The bone marrow is the primary site where stem cells produce blood cells. Under a general anesthesia, a hollow needle is used to extract marrow from the hip bone. It is then frozen and stored until the recipient completes high dose chemo or radiation. When transplanted (through the patient's vein, similar to a blood transfusion), the marrow migrates to the interior portion of the patient's bones and the stem cells then begin to produce healthy blood cells. This is known as engraftment.
- **In the bloodstream** – These are called peripheral blood stem cells (PBSC). Drugs called colony-stimulating factors or growth factors are injected to move stem cells from the marrow into the bloodstream. No general anesthesia is needed for collection. The stem cells are collected using apheresis (blood is removed through a catheter and circulated through a machine which removes the blood containing the stem cells and returns the other blood cells back to the patient/donor). This outpatient procedure may be repeated more than once to ensure that enough stem cells are collected.

The cells are then frozen and stored until the recipient completes high dose chemo or radiation. When transplanted (through the patient's vein, similar to a blood transfusion),

the stem cells migrate to the interior portion of the patient's bones and begin to produce healthy blood cells. This is known as engraftment.

- **In cord blood** – Cord blood is the blood that remains in the umbilical cord and placenta after a baby is born. It has been found to be a rich source of stem cells. Thus, expectant families may choose to donate their baby's cord blood for public use or bank it for their own family use (this usually involves storage fees – talk to your health care team for more detailed information about cord blood banking). Cord blood must be collected immediately after a baby is born. The cord is clamped and cut, and a needle is inserted into the umbilical vein to collect the blood and stem cells. Because these stem cells are collected at birth, they are less likely to be contaminated with viruses or environmental toxins. The collected cells are then frozen and stored until the recipient completes high dose chemo or radiation. When transplanted (through the patient's vein, similar to a blood transfusion), the stem cells migrate to the interior portion of the patient's bones and begin to produce healthy blood cells. This is known as engraftment.

Side effects of bone marrow/stem cell transplant vary depending on the person and the specific treatment course. Common side effects include nausea, vomiting, mouth sores, diarrhea, cramps, hair loss, graft versus host disease (for allogeneic transplants) and high risk of infection.

Immunotherapy/Biological Therapy

Sometimes, the body's own immune defenses can be used to attack cancer. Scientists have learned to manufacture biological response modifiers in labs. These substances change the way the body's immune defenses respond to the cancer threat. There are several types of immunotherapy, including:

- **Interferons** – These chemicals boost the body's immune response, and may stop cancer cells from growing (or make them behave more like normal cells).
- **Interleukins** – These chemicals can stimulate growth of the body's immune cells, especially lymphocytes (a type of white blood cell). The body is then better able to fight cancer cells.
- **Monoclonal antibodies** – Specific antibodies are created to match antigens on specific tumor cells. They can be linked to anti-cancer drugs or radioactive substances and then carry these poisons directly to tumor cells. Normal cells are spared because they don't carry the foreign antigens. This reduces side effects.

Clinical Trials

Clinical trials are research studies conducted with cancer patients, usually to evaluate a new treatment. Standard treatments (the ones currently being used) are often the building blocks for new and better treatments. Clinical trials often take what has worked in the past and try to improve upon those methods.

Clinical trials occur in different phases:

- **Phase I** – This is the first step in testing a new treatment in humans. It has been well tested and has shown promising results in lab and animal studies, but nobody knows how humans might react. Researchers are looking for the best way to administer the new treatment, and they are watching for any harmful side effects. These studies are only offered to patients who would not be helped by other known treatments.
- **Phase II** – These trials focus on whether the new treatment has any anti-cancer effect. Only a small number of people participate in Phase II trials because of the unknowns involved.
- **Phase III** – If a treatment has shown promise in Phase II, it moves to Phase III, where the results (like survival rates and side effects) of people taking the new treatment are directly compared with results of people taking the standard treatment. Phase III trials may involve hundreds of people from all across the country.
- **Phase IV** – In this type of study, the new research treatment becomes part of the standard treatment (e.g. a new drug that has been proven effective may be used in conjunction with other chemotherapy or radiation).

Clinical trials fuel the advancement of medicine. They help cancer researchers create safe and effective treatment for patients. Participation in clinical trials is voluntary and should be based on a clear understanding of the possible risks and benefits involved. For information on the latest clinical trials throughout the country, speak with your physician and the National Cancer Institute's Cancer Information Service at 1.800.4.CANCER.

Complementary & Alternative Therapy

Standard or conventional treatments are those widely accepted and practiced by the mainstream medical community. They have been tested following a strict set of guidelines and have been found to be safe and effective. While the terms are often used interchangeably, complementary therapy most commonly refers to supportive methods used in addition to standard or conventional treatment, while alternative therapy most commonly refers to methods used instead of conventional or standard treatment.

Complementary and alternative therapies are used in an effort to control cancer symptoms, to improve well-being, and (some people believe) to even cure disease. Commonly used methods include guided imagery and visualization, meditation, acupuncture, acupressure, dietary supplements and massage therapy.

Because less is known about the safety and effectiveness of complementary and alternative therapy, it is extremely important to discuss options with the patient's health care team. Remember, there are no sure cures. A person must learn what the benefits and risks are with the therapy, what the side effects are, how the therapy might interfere with conventional treatment, and whether the therapy is covered by health insurance.

TAB NAME: "HEALTHCARE"

Working with Your Health Care Team

From diagnosis to beyond treatment, you will interact with a variety of health professionals. Together, you form a health care team. This section will help you understand who the key team members are and how to get the most out of your interactions with them.

Key Team Members

Your health care team is comprised of professionals who, when working together, ease patients and families through treatment and the coping process. Each of the people listed below offers a unique service and can play an important role in the patient's care.

Physicians

Physicians are the people who plan the patient's care. They can examine the patient, order necessary tests, choose a treatment course and prescribe needed medication. Physicians are supposed to keep the patient and family informed and involved throughout the treatment process.

An oncologist is a physician who specializes in the treatment of cancer, while a hematologist specializes in the treatment of blood disorders. Once a diagnosis is made, people with leukemia, lymphoma and the other disorders mentioned in this packet most often receive their treatment from a hematology/oncology physician – a doctor trained to treat cancer of the blood and blood-forming tissues. A patient may also see a radiation oncologist (a specialist in the use of radiation therapy to treat cancer) if radiation is deemed necessary.

A patient and family may also interact with physician's assistants, residents, fellows and specialists in fields other than cancer. It can be overwhelming to keep track of each of these professionals. Speak with your health care team for a complete description of each person's role in your care.

Nurses

Nurses are the professionals who are usually responsible for implementing the plan the physician has set for the patient. They provide much of the "hands-on" care and often act as a liaison for all of the members of the health care team. Nurses are trained to administer medication, monitor side effects and assess the patient's well-being. Advance practice nurses (clinical nurse specialists or nurse practitioners) are able to provide more "in depth" management of the patient's care, and may be able to prescribe medication. They are Master's prepared and have received advanced training.

Most major treatment centers have oncology nurses (nurses who specialize in cancer). Many of these nurses are also able to provide families with helpful educational materials and referrals to support services throughout the community.

Social Workers

Social workers connect patients and families with the emotional support and practical assistance they need. These professionals are trained to provide counseling as families face trying times, and they're often the leaders or facilitators of support groups. Social workers are also able to explain hospital policies and procedures, and can link families with useful government and community services (and guide them through necessary application procedures). Major treatment centers usually have oncology social workers who specialize in meeting the needs of families affected by cancer.

Pharmacists

Pharmacists prepare medications needed for specific treatments and for maintaining the patient's overall health and comfort. They are trained to make sure appropriate dosages are prescribed and to watch for potentially harmful drug interactions. Pharmacists are available to answer questions about prescription and over-the-counter drugs, and may be able to suggest strategies for reducing unpleasant side effects associated with certain medications.

Clergy

Many people who must cope with serious illness find spiritual counseling and prayer helpful. In fact, some studies have shown that people who feel spiritually "connected" experience less depression, anxiety and even pain as they deal with cancer and its treatment. Most hospitals offer clergy or pastoral care services for patients and caregivers who want to receive sacraments or spiritual guidance. Most often, these services are available to people of all faiths. Clergy also play a role in assisting the health care team with ethical issues.

Psychologists & Psychiatrists

A psychologist has an advanced degree in psychology and counseling, while a psychiatrist is a medical doctor who specialized in mental health and can prescribe medication. Both are trained to assist patients and family members who are feeling sad, anxious or depressed. Some psychologists and psychiatrists specialize in chronic illness, so they are particularly aware of the emotional and psychological issues that cancer patients and caregivers face.

Dieticians/Nutritionists

Dieticians and nutritionists can evaluate the patient's diet, determine any deficiencies, and suggest a plan that will help the patient get the nutrients needed to feel better and stay healthy. These professionals can also provide hints for increasing the patient's appetite so they can get recommended nutrients, even if experiencing illness or treatment-related problems with the mouth, throat or stomach. Dieticians and nutritionists may also be able to help family members maintain healthy diets as they face stresses on their time and emotions.

Rehabilitation Specialists

Sometimes cancer and its treatment can cause extensive physical changes in a patient. Physical therapists can help a patient maintain proper muscle tone and adapt to changes in the body. Occupational therapists can help patients use their bodies effectively and efficiently in order to complete activities of daily living (like eating, dressing and writing). Speech therapists can help people adapt to changes in the mouth and larynx so that they can still communicate verbally. Rehabilitation specialists can also guide people to adaptive/medical equipment they may need and can suggest appropriate leisure activities.

Depending on where you receive treatment, you may or may not receive an automatic “referral” to each of these health care professionals. If you have not been offered some of the services above, but feel that you would benefit from them, talk to your physician or nurse to see how you may arrange an appointment. If the services are not available through your treatment center, ask about locating professionals in your community. It’s also wise to ask if there are any fees associated with these services, and if your health insurance will cover them.

Basic Patient Rights

There is one final member of the health care team that has not yet been mentioned – you. You are a partner in your care. Your expertise lies in knowing how you feel, and which type of information and insight will be helpful for you as you cope with your illness and its treatment. Some people want to gather as much information as possible, while others feel threatened by “knowing too much.” Your feelings are legitimate, no matter where you fall on this spectrum. But as a member of the health care team, it’s your responsibility to let the other members know what your feelings are. Health professionals are looking to you to set the pace. Don’t be afraid to speak your mind, no matter what you’re thinking.

Before communication issues are discussed, it’s important to know that all patients have basic rights. When you are aware of these rights, you become more confident with your ability to determine whether or not you are receiving quality care. This helps make you an empowered member of your health care team.

As a patient, you have the right to:

- **Considerate and respectful care** – Members of your health care team should be sensitive to your feelings, values and needs at all times.
- **Be treated without discrimination** – You cannot be denied access to care because of your gender, race, religion, sexual orientation or financial status.
- **Informed consent** – You should receive all of the information you need to make a decision before you agree to any procedure or treatment. This includes explanations about your medical condition, procedure and treatment options, potential risks and benefits, potential side effects, possible outcomes, estimated costs and the consequences of not accepting the proposed procedure or treatment.

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- **Privacy** – Any exams, tests or discussions about your case should be conducted discretely and in a manner that ensures your dignity. People not directly involved in your care must have your permission to be present.
 - **Confidentiality** – Medical professionals should not needlessly talk about your personal life or medical situation. Except as is required by law, information about you must be kept private. It cannot be shared with anyone who is not directly involved in your care (including family members) without your permission.
 - **A second opinion** – Most doctors welcome this (and can suggest another physician for the job), and many insurance carriers cover it. When you have a serious illness, you will make some of the most important decisions of your life. Thus, you need to make sure you've gotten the best advice you can. A consultation with another doctor can reassure you (and your physician) that the first opinion is on track. If, after you receive a second opinion, you decide to change doctors, your original doctor is legally obligated to provide your new doctor with any existing medical records.
 - **Make advance directives** – Advance directives help make your wishes clear if you ever become physically or mentally unable to speak or decide for yourself. A living will lists your instructions for the type of care you want if you are ever terminally ill, while durable power of attorney lets you name another person who will make decisions about your care if you are no longer able to do so. See your social worker or lawyer, or contact CLF for more information.
 - **Refuse care** – You are allowed to refuse treatment to the extent permitted by law. You should also be informed of the medical consequences of taking this action.
 - **Understand your bill** – You should receive a full explanation of your medical bill. This includes a description of the costs of all appointments and procedures, a report detailing which costs have already been paid and by whom, and a statement that explains who is responsible for any remaining charges (you or your insurance company).

If you feel any of these rights have been violated, you also have the right to speak out about it and seek a resolution. Simply discussing your concerns with your health care provider can help resolve most issues. If this does not work, contact your treatment center's patient advocate representative or mediator for additional assistance.

Communication Issues

As always, communication is a two-way street. Members of your health care team are not just treating a disease – they are treating a person who has values, opinions and concerns, as well as a health condition. Your questions and your input are important and necessary, and they must be made known to your health care team. By communicating and working together, you can establish a care plan that satisfies your needs.

Understandably, it's sometimes a bit intimidating to think of yourself as a partner in your care. This fear can create some barriers to effective communication.

Common Thoughts and Feelings that Can Block Effective Communication

My doctor is going to think my questions are dumb.

As the old saying goes, the only dumb question is the one that isn't asked. This is a new and potentially frightening situation for you and your family. You are bound to have a lot of questions – some simple, and some complicated. The members of your health care team understand this, and they should be there to listen to you and to answer your questions to the best of their abilities.

Always remember that, as a patient, you are a health care “consumer.” Think of how you function as a consumer outside of the health care setting. If you purchase a new car, you may ask the salesperson a number of questions. “Which colors are available?”...“What was the most recent crash test rating of this vehicle?”...“How much difference can I expect between a four-cylinder and a six-cylinder engine?” These and other questions help you to make an informed decision. As a consumer, it's your right to make inquiries and expect reasonable responses. If you're not given that opportunity, or if your questions are dismissed, it's also your right to seek services elsewhere. The same is true in the health care system. Don't be afraid to ask questions about issues surrounding your diagnosis. Your life and your health are the most valuable goods you'll ever have.

This is all so overwhelming that when I do get the opportunity to ask questions, I don't know what to ask, or I can't remember what my questions were. And once I get my questions answered, I soon forget what was said.

This is perfectly understandable. Dealing with a serious illness causes many strains on your emotions. Combine this with the fact that you're receiving all kinds of new information, and it's easy to see why it may be hard to concentrate. However, acknowledging this ahead of time gives you the opportunity to develop strategies that will help you get your questions answered.

- **Write out a list of questions before your appointment** – Set aside a period of time to think about what you want to know before you're “on the spot.” Simply writing out your questions can help organize your thoughts and help you feel “in control” when you arrive at your appointment. And don't forget to write down the answers you get. Writing things down reinforces them in your mind, and provides you with something tangible you can refer back to as needed. Some suggested questions are listed at the end of this section.
- **Ask a friend or family member to go with you** – Having another person at your appointment can help make the visit less stressful. It also provides another set of ears to help you remember what your doctor says. It's important to pick a person who supports you, but is still able to be objective. If possible, meet with the person before the appointment and discuss your list of questions. Talk about this person's role – do you just want them to listen and take notes, or do you want them to ask questions, too? Share with your companion what you hope to get out of the meeting, and ask them to alert you if it seems like any of your concerns have not been addressed.

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- **If possible, bring a tape recorder** – Many doctors allow patients to tape record their visits. This is the most accurate way to recall what was said, because it gives you an exact playback of your appointment. Plus, you get to listen to it in a more relaxed atmosphere. It may also be helpful to share parts of the tape with others.
 - **Get copies of educational materials** – Ask your health care team (usually a nurse or social worker) if there are pamphlets, visual aids, books, or other materials that will further explain the issues you discussed. These materials may provide you with additional information, or simply reinforce the information you already received. And don't forget to check the back of this packet for a complete listing of the materials CLF carries through our Resource Room.

Even when I do ask questions, I don't always understand the answers I get.

When a lot of information comes your way, it's easy to get stuck nodding your head and saying, "Uh-huh," even when you're not really sure you comprehend what is being said. It's important that you let health professionals know when something is unclear. Remember, you are the consumer and you have the right to understand what is happening to your body. This helps you become an informed partner in your care.

- **Say, "I don't understand."** – It's as simple as that. Be direct and be assertive. If a health professional is using technical terms, let them know you don't understand, and ask for an explanation in "plain English." And don't feel silly if you've received a response that doesn't contain big, scientific words, and you still don't understand. Simply ask the health professional to re-explain. If this doesn't help, ask if there is another member of the health care team who may be able describe the concept in a way that makes more sense to you. Ask for any helpful educational materials, as well.
- **Repeat or rephrase information you receive** – Start by saying, "Let me make sure I understand what you're saying..." Then make yourself re-state what the doctor has said. This will help to reinforce concepts in your own mind. But more importantly, it lets the doctor know if you really have understood the explanation, and gives them the opportunity to correct any misunderstanding.

My doctor doesn't have time to answer my questions.

It's true that doctors are busy people. You can't demand 100 percent of your doctor's time – your doctor has many patients to care for. But your health is at stake, and you need to have your questions answered.

- **Make it known ahead of time if you have a lot of questions** – If the doctor is aware in advance that you may need extra time, they may be able to schedule a longer appointment for you. It may even be helpful to send your list of questions to the physician ahead of time.

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- **Prioritize** – A typical doctor’s appointment is only 15 minutes in length, including any actual examination (initial oncology consultations are longer). Be sure to get complete answers to your most important questions first.
 - **Find out when your doctor is available to spend more time answering questions** – Can you schedule a sit-down appointment just for asking questions? Is it possible to set up a phone consultation? It’s helpful to discuss important issues when you’re not under time pressure. You need adequate time to get a well thought out response, ask follow-up questions and make necessary decisions.
 - **Find the appropriate person for the question** – Remember, your physician is part of a team. It may be more effective and efficient to ask a nurse, social worker or pharmacist some of your questions. Start by asking, “Is there a better person to answer this question?”

I don’t want to bother my health care team with all of the details.

Doctors and nurses are not mind readers. If a health professional asks you how you’re feeling, don’t say “Fine” if you’re not. It’s extremely important to report new symptoms and any changes in how you feel. This gives your health care team the information needed to best manage your treatment and address your concerns. Your feedback is vital to your well-being.

I shouldn’t question or disagree with my doctor. The doctor is in charge.

Again, the important word to remember is “partner.” While you probably don’t have the background to make a diagnosis, prescribe treatment or interpret medical tests, you are the only person who really knows what your values are, and what you’re actually feeling, both physically and emotionally. Voicing your opinions and concerns is the only way your medical team can truly gain insight into your needs as a patient. When you are able to do this, you are able to work together as partners to establish a treatment plan that meets your needs and respects your values. If your health care team is not willing to address your concerns, you have the right to find health professionals who will.

Questions for Your Health Care Team

Below is a list of potential questions that may be helpful as you meet with members of your health care team. It is important to read these questions before you get to the consultation or appointment – that way, you’ll be prepared, and once you arrive, you can focus your full attention on the health professionals’ responses. These questions are only building blocks. The answers that you get may spark new questions. Be sure to follow up as needed. And don’t forget that every person is different. Take the time to figure out what your own concerns are, and develop questions that will be helpful for your specific situation. This guide includes a notepad for you to write down your own questions.

About the Diagnosis

- Which tests determined that I have cancer/pre-cancer? How accurate and reliable are these tests?
- Which type of cancer/pre-cancer do I have? Which parts of the body does it affect? Is there a specific diagnosis? Is this diagnosis known by any other names?
- How certain is the diagnosis?
- Which stage is my diagnosis in? How is this determined?
- Do I need any further testing? Describe these tests. What are they for? What do they involve? Are there any risks? How soon will they take place?
- What is my prognosis? Which factors contribute to your opinion?
- Are there any organizations that provide additional information, assistance, and support for people with this diagnosis?
- Additional questions about the diagnosis:

About Treatment Options

- Which treatment options are available to me? Which do you recommend and why?
- What does this treatment involve? Please explain the procedures.
- Where will I receive treatment (inpatient, outpatient, at home)? How often will I receive this treatment, and for how long?
- What is the goal of this treatment? To cure/get rid of the disease? To control my symptoms? To increase my comfort level? How likely is it that the goal will be achieved?
- Are there any short-term or long-term risks associated with this treatment?

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- Which side effects are commonly associated with this treatment? When do they begin, and how long will they last? Is there anything I can do to lessen or control unpleasant effects?

Nausea/vomiting

Diarrhea

Hair loss

Skin changes

Mouth problems

Fatigue

Pain

Fertility changes

Changes in cognition or mental capability

Other _____

Other _____

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- Are there any “warning signs” (serious symptoms or side effects) that I should report right away? Who should I contact and how do I reach that person?
 - Are there any other medical check-ups (including dental check-ups) that I need to have before my treatment begins? Why?
 - Before, during or after treatment, are there any changes I will have to make to my work life, family life or leisure activities? Are there any specific behaviors I need to change?
 - Will this treatment affect any pre-existing medical conditions I have? Will it interfere with the treatment or medication I take for those conditions? Will I have to adapt in any way?
 - How will we know if the treatment is working? How will we know if the goals have been met?
 - How much will this treatment cost? Is it covered by my health insurance?
 - What would happen if I chose not to receive treatment?
 - Additional questions about treatment options:

About the Physician

- What are the qualifications and credentials of the health professionals who will be involved in my treatment? Are the physicians board certified?
- How much experience do you and the rest of the team have treating people with diagnoses like mine? In the last year, how many people have you treated with my diagnosis?
- How do I reach you or where do I call...
 - If there is a medical emergency?
 - When I need to schedule appointments for treatment and check-ups?
 - When I have questions about my diagnosis, treatment or general concerns?
 - After regular office hours (in the evenings or on weekends)?
 - If you are not available?

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- Are you part of a group practice? If so, under which circumstances will your partners see me? What are their qualifications/credentials? How will you communicate about my care?
 - What are your expectations of me as a patient? How can we best work together?
 - Who would you suggest I see for a second opinion?
 - Additional questions about the physician:

TAB NAME: "COPING"

Coping with Common Side Effects of Cancer Treatment

It's true. Chemotherapy, radiation therapy and other forms of treatment work to kill cancer, but they can also produce some unpleasant side effects. Depending on the type and amount of treatment you receive, and how your body reacts to it, you may experience none, some or all of the side effects described below. Each person is different.

Before you start treatment, ask your health care team which side effects are most likely to occur with your particular treatment course, how long they might last, how severe they might be, and when you should seek medical attention for them.

The information below will provide you with some basic tips for coping with some of the most common side effects of cancer treatment. It is not meant to substitute for advice from your health care team.

Nausea/Vomiting

Treatment can cause nausea and vomiting by affecting the stomach, the area in the brain that controls nausea and vomiting (the chemo-receptor trigger zone or CTZ) or both. Radiation to the abdomen area can damage the rapidly dividing cells that line your stomach. Some chemotherapy drugs can have the same effect. This upsets your stomach, making you feel ill. In addition, some anti-cancer medications can make your body release chemicals (like dopamine and serotonin) that stimulate the CTZ and cause nausea and vomiting. Reactions vary between individuals, and depend on dosages. Sometimes, just the anticipation of treatment, or a reminder of it, can make a person nauseated, or even make them vomit. This is known as anticipatory nausea and vomiting (ANV).

Tips

- Talk to your health care team about anti-nausea medications (antiemetics). Different medications work for different people, and sometimes a combination of drugs works best. Whatever the case, be sure to follow the instructions on the label and the instructions given by the nurses and doctors.
- If nausea is a problem in the morning, try eating dry foods like toast, pretzels or crackers before you get up (unless you have mouth or throat sores).
- Avoid fatty, greasy, or spicy foods, dairy products and acidic foods. These are all hard for the body to digest and may make nausea worse.
- Stick to bland foods like cottage cheese, potatoes, canned peaches or pears, angel food cake, crackers or plain, baked chicken with the skin removed.
- Eat foods cold or at room temperature. Hot foods tend to smell stronger. Strong smelling foods add to nausea.
- Eat several small meals throughout the day, rather than two or three big meals. It's better for digestion. Eating frequent, light meals keeps something in your stomach, but keeps you from feeling too full.

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- Some foods are better at easing upset stomachs. Try ginger. It contains chemicals that may reduce nausea. Ginger ale, ginger cookies, and hard candies could help suppress symptoms.
 - When nauseated, stay out of the kitchen to avoid food odors. It's best not to associate food with sickness. Instead, try to get some fresh air, whether by opening a window or stepping outside. Breathe deeply and through your mouth. This all helps you take in more oxygen, which can calm the stomach.
 - Stay away from your favorite foods when you're feeling nauseated. You may start to associate those foods with feeling sick, or you may even develop food aversions.
 - Sip cold, clear liquids like water, sports drinks, unsweetened fruit juices or light-colored sodas with the fizz let out of them (carbonation can upset the stomach). Sip liquids slowly throughout the day (using a straw helps) instead of drinking with meals. This helps the stomach feel less full at meal time.
 - Get rest. After meals, though, rest in a chair. Try not to lie flat for about two hours after eating. Resting in a seated position helps move food through the digestive tract.
 - Unpleasant tastes in your mouth can upset your stomach. Rinse the mouth frequently with water, or try sucking on ice chips, popsicles or mints.
 - Wear loose-fitting clothing. If tight clothes put pressure on the stomach or throat, they can add to stomach upset.
 - Find a distraction. Watch television, listen to music, read a book, play a game or talk to a friend in order to divert your attention from feeling nauseated.

Mouth/Throat Sores

Treatment that kills cancer cells can also hurt healthy cells, like the white blood cells that fight off mouth infections, and the mucosal cells that line the mouth and throat. When these cells are damaged, it leads to painful mouth or throat sores and tender gums. This can prevent a person from getting the food and drink they need to maintain adequate nutrition and hydration. Check with a doctor first to make sure that the soreness is truly a treatment side effect and not a separate dental problem. Then follow the tips below.

Tips

- Keep the mouth as clean and free of bacteria as possible. After eating, gently brush the teeth, tongue and gums with a soft, clean toothbrush. Rinse the mouth every two hours or so with a salt water rinse (two cups of warm water with 1/2 teaspoon of salt and 1/2 teaspoon of baking soda). This will remove food and bacteria build-up and promote healing. If the teeth and gums are sore, your dentist may be able to suggest a special product for cleaning the teeth.
- Talk to your health care team about prescription mouth rinses that help prevent infection and ease soreness. Also ask about pain medication that may make eating and swallowing less troublesome.

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- Talk to your health care team about anesthetic lozenges, sprays and liquids that can numb the mouth and throat before eating and swallowing.
 - Avoid rinses with alcohol or peroxide in them. They dry the mouth.
 - Avoid acidic fruits and juices (like orange, grapefruit or pineapple), spicy or salty foods (like potato chips or seasoned tacos), and rough, dry or coarse foods (like raw vegetables, toast or crunchy peanut butter). These can all irritate the mouth and make sores worse.
 - Stick to soft foods that are easy to chew and swallow, like applesauce, cottage cheese, yogurt, mashed potatoes, macaroni and cheese, milk shakes, pudding, gelatin, scrambled eggs, oatmeal, pancakes and ice cream.
 - Cook all meats and vegetables until they are soft and tender. Cut foods into small pieces, or consider blending, grinding or mashing them. Mixing foods with gravies, sauces or butter also makes them easier to swallow.
 - Eat foods cold or at room temperature. Hot items can irritate a tender mouth.
 - Suck on ice chips and drink plenty of liquids. Using a straw and tilting your head back can make it easier to swallow.
 - Avoid smoking, chewing tobacco and alcoholic beverages.
 - The lips can become dry and cracked when it's difficult to swallow. Use a lip balm, petroleum jelly or cocoa butter to keep lips moist.

Diarrhea

The cells that line the digestive tract grow and divide rapidly, which means that they are often damaged during chemotherapy or during radiation to the abdomen. This causes diarrhea (loose or liquid stools). Having diarrhea itself is unpleasant, but it is also troublesome because the loss of water and other nutrients can lead to dehydration.

Tips

- Call your doctor if you have diarrhea that is accompanied by pain, cramping or blood in the stool, or if diarrhea lasts for more than 24 hours.
- Do not take any over-the-counter antidiarrheal medicines (like Immodium or Kaopectate) without asking your doctor first.
- Keep the area around the anus clean and dry. Wash it with mild soap and warm water after every episode, and gently pat dry. If the anus is sore, check with your health care team to see if there are any creams or ointments that may help.
- Drink plenty of fluids to replace those you have lost. Mild, clear liquids are best. This includes water, apple juice, sports drinks, ginger ale, clear broth, peach juice and weak, decaffeinated tea. To avoid irritating the digestive tract and making diarrhea worse,

serve liquids at room temperature (avoid very hot or very cold drinks), drink them slowly, and let the fizz out of any carbonated liquids.

- Stay away from high fiber foods (like bran, raw vegetables, beans, popcorn, nuts and whole grain breads), greasy, fatty, or fried foods, spicy dishes and alcoholic beverages. Limit milk and other dairy products. They can all upset the digestive tract and make diarrhea worse.
- The BRAT diet (bananas, rice, applesauce and toast) is often suggested for coping with diarrhea. In general, low-fiber foods like these are best. Items like white bread, noodles, cottage cheese, canned fruit without skins, mashed potatoes, skinned turkey or chicken and fish are also low in fiber and help control diarrhea.
- Potassium and sodium are important minerals that the body loses during diarrhea. To replace sodium, drink sports drinks or clear broth, and eat crackers and pretzels. To replace potassium, drink peach or apricot juice, and eat bananas or potatoes without the skins.
- Eat several small meals throughout the day, rather than two or three big meals.

Constipation

Constipation occurs when the normal squeezing motion of the intestines is slowed down, forcing the stool inside to sit longer and get harder and dryer. This makes it difficult to have a bowel movement. Constipation may be a result of anticancer drugs or pain medications, or it may result from decreased physical activity and poor nourishment.

Tips

- Talk to your health care team about medicines that can relieve constipation. Do not take over-the-counter fiber supplements, stool softeners or laxatives without checking with your doctor first.
- Try to have a bowel movement at the same time every day (mornings and the hour after meals are usually best). This helps establish regularity.
- Drink plenty of fluids – eight to ten glasses a day – to help keep your stools soft. Hot drinks are particularly helpful, especially about 30 minutes before your usual time for a bowel movement. A daily serving of prune juice can also help.
- Eat foods that are high in fiber, including whole grain breads and cereals, dried fruits (like raisins and prunes), raw vegetables, potatoes with the skins, dried beans, nuts and popcorn.
- Get some exercise, like walking, every day. Talk to your health care team about the amount and type of exercise that is appropriate for you.

Hair Loss

Hair loss (alopecia) is a common side effect associated with chemotherapy and radiation therapy. These treatments affect rapidly growing cancer cells, but they also affect normal cells that divide quickly, like hair follicles. When the cells in hair follicles are damaged, they produce weak, brittle hair that may fall off at the surface of the skin, or at the root itself. The result can be thinner hair, or complete hair loss.

Not all chemotherapy drugs cause hair loss, but when they do, hair loss can occur all over the body (eyebrows, eyelashes, face, legs, arms, underarms and pubic area) – not just on the head. Although the hair follicles are damaged immediately, hair loss usually doesn't occur until after a few chemo treatments. It may fall out gradually, or in clumps. When chemotherapy stops, hair usually starts to grow back and it may even have a different texture or color than the hair you lost. Radiation can also cause hair loss, but only in the area being treated. The amount of hair that grows back depends on the amount and type of radiation you receive.

Tips

- Hair is even more fragile when it's wet, so be sure to wash it gently, using a mild shampoo – one that's designed for overtreated or damaged hair.
- Use a soft hair brush.
- Avoid things that will make damaged hair even dryer, like hot blow dryers, hot curlers and curling irons, peroxide or hair dye, permanents and hair spray.
- If you have long hair, consider cutting it short before treatment starts. This will make treatment-related hair loss less drastic and easier to manage. Shorter hair may also "camouflage" thinning. Longer hair is heavier, so the weight pulls it flatter to your head. Shorter hair, on the other hand, tends to have more lift, so it looks thicker and fuller.
- Place a towel or small blanket on your pillow at night. This will make it easier to collect hair that has fallen out.
- The scalp is extremely sensitive to sunlight. Be sure to wear sunscreen (with an SPF of 15 or above), or cover your head to protect your scalp when outdoors.
- Everybody is different. Some people who lose their hair prefer to cover their heads, some would rather leave their heads uncovered, while others prefer to switch back and forth. It's your choice. Do whatever makes you comfortable. You are in charge of your body and your appearance.
- If you do choose to cover your head, remember that CLF has a reimbursement program to help you cover the cost of wigs and other head coverings. Choose scarves, turbans, hats, caps, wigs or other hair prosthetics.

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- If you choose to purchase or borrow a wig or other hairpiece, it may be helpful to take along photos that show what your hair normally looks like. Take photos to show front, side and back views of your hair to help ensure a close match. On the other hand, you may decide to take this as an opportunity to try a completely different look. The choice is yours.
 - There may be some places where wearing head coverings is normally not an accepted practice (schools or workplaces). If it's important to you to be able to wear a hat, cap or turban, speak with the appropriate officials about your circumstances. In the grand majority of cases, permission will be granted.

Fatigue

Cancer patients commonly experience fatigue. This is usually more than a simple drowsy feeling. If you're a cancer patient, you may describe it by saying, "I just don't feel like myself." Everyday activities make you feel short of breath and you tire easily – and this tiredness doesn't seem to go away after a good night's sleep. This kind of fatigue makes you feel weak and affects your ability to concentrate.

The fatigue that cancer patients experience can be caused by a number of factors. It can be a symptom of anemia. Anemia occurs when there are too few red blood cells (from the cancer itself, or from the treatment), which means that the body's tissues don't get enough oxygen to do their work. Fatigue can also result from the body working overtime to rid itself of cancer cells and repair healthy tissues that have been damaged by treatment. It can be a side effect of nausea or pain medication. Nausea, vomiting and diarrhea can have a negative effect on nutrition, which can lead to fatigue. And emotional factors like stress, anxiety, fear and depression can certainly affect fatigue. Whatever the case, fatigue is a legitimate issue that needs to be taken seriously.

Tips

- Talk to your doctor to see if your fatigue may be caused by anemia. If this is the case, your doctor may be able to prescribe iron pills, vitamin supplements or medications designed to stimulate production of red blood cells. Anemia is treatable.
- Take several short catnaps or breaks throughout the day, rather than one long rest period. This gives your heart more chances to beat slower and to help you save your energy.
- If possible, set regular times to rest and sleep. This will help your body come to expect a routine, which helps make sleeping easier.
- Prioritize. Make a list of the things that you must get done. Then, make a list of the things that you should get done, but that can realistically wait until another time if necessary. Set a comfortable pace and do the things that you must get done. Spread these activities out and plan rest breaks in between. Then, only if you're feeling up to it, do some of the things on your "should list."

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- Let others help you. Ask family and friends to pitch in with tasks like housekeeping, meal preparation and grocery shopping, so that you can have more energy to complete the activities you really enjoy. People are often looking for a way to help out – take them up on the offer!
 - Continue to participate in the activities you enjoy, but find strategies that require less energy. If you normally play in a sports league, go and cheer your team on at their next game. If you're a gardener, try working from a seated position. If you like to socialize with friends, set a time limit on how long visits should last.
 - Find activities that are less strenuous, like listening to music, reading or simply enjoying nature or wildlife in your yard. These activities will help you relax and sleep easier.
 - Take short walks or talk to your health care team about some other light exercise that may be appropriate for you. Regular, light exercise will help increase your energy levels. Plus, keeping active during the day helps encourage normal fatigue at night, which makes sleeping easier.
 - Eat a well balanced diet (including iron-rich foods like spinach and red meat) and drink plenty of fluids. Eat several small meals throughout the day, rather than two or three big meals. Small meals take less energy to digest.
 - Keep a journal to document what you do during the day and to keep track of your energy and fatigue levels. Once a few days have passed, review your journal entries to see if you can identify any patterns. Are there certain times when you consistently feel more energized? Do certain activities consistently make you feel exhausted? Use this information for planning upcoming days to maximize energy and minimize fatigue.
 - Be honest about your fatigue-related needs and limitations with friends, family and employers. Work with them to establish realistic goals.

Pain

Pain is any sensation that hurts. For cancer patients, pain can result from the cancer itself (like a tumor causing pressure on a nerve, bone or organ), from cancer treatment, from the side effects of cancer treatment or from a related medical issue.

Whatever the cause, most cancer pain can be eliminated, and all cancer pain can be controlled. There are many different methods, including over-the-counter pain relievers, prescription pain relievers, surgery, relaxation techniques, imagery, distraction, massage, acupuncture and more. Only you and your health care team can decide which methods might be best for relieving your pain – but you have to work together.

Tips

- Always check with your health care team before you take any action to relieve your pain.
- Be able to describe what you're feeling. Your description is what will help your health care team determine the appropriate course of action. Consider keeping a pain journal. Writing down your answers to the following questions is a good start:
 - Where is your pain located? Is it in more than one area?
 - When did it start? Over time, has it gotten worse, stayed the same or improved?
 - Is the pain constant, or does it come and go? If it comes and goes, how often does it occur and how long does it last? Is there anything predictable about it?
 - What does the pain feel like? Do any of the following words describe it: Sharp, burning, aching, shooting, pounding, prickly, tight, shock-like, stabbing, pinching, dull, throbbing, tingling, heavy?
 - How severe is the pain? On a scale of 0 to 10, where 0 is no pain at all and 10 is the worst pain you could imagine, how would you rate your pain?
 - How does your pain affect your everyday life? Is it preventing you from doing any of your daily activities? Is it making it difficult for you to concentrate? Is it making you want to stay away from others? Is it affecting your emotions?
 - Is there anything that relieves your pain?
 - Is there anything that makes the pain worse?
- Remember your rights. If you have pain, you have the right to have it taken seriously. Refer to Section 3, "Working with Your Health Care Team," for useful tips.

TAB NAME: "EMOTIONAL ISSUES"

Emotional Issues Associated with Serious Illness

Now that some of the physical side effects of cancer and its treatment have been discussed, it's important to talk about emotional issues. This section will help you identify some of the common emotional responses that you and those around you may experience. It will also provide you with some potential strategies for helping you cope with these emotions.

Common Emotional Responses

Listed below are some of the feelings experienced by both patients and family members who are affected by cancer. Different people experience these emotions at different times and with varying levels of intensity, but they are normal, common reactions. They are described here in order to help you understand that you are not alone.

Shock/Confusion

You may not remember much of what was said after the doctor gave you the diagnosis. The word "cancer" or "pre-cancer" probably blocked out all other information. People often describe this period as being in a numb, dream-like state. This is the brain's response to shock. The brain protects itself with numbness and confusion in order to prevent emotional overload. It prohibits the intake of too much threatening information, but may leave you thinking, "What just happened here?" Your health care team understands this, and is usually willing to repeat explanations as necessary. For more information about obtaining and remembering information, turn to Section 3, "Working with Your Health Care Team."

Denial

For a short period after diagnosis you may think, "This can't be happening. There must be some mistake." It's almost impossible to believe that you or your loved one is going to be battling a life-threatening illness. Denial is a way to avoid thinking about the seriousness of the situation. Denial may actually help you get through the first few days after diagnosis. However, denial that lasts too long can be problematic. Continuing to talk and think about things as if nothing is wrong will not make the problem go away. Gradually, acceptance must occur so that you and your family can adjust to life with cancer and its treatment. Ignoring the circumstances makes it almost impossible to provide or accept emotional support when it is greatly needed.

Fear

You will probably experience a number of different fears: How will you be able to handle the stress? How will friends and family react? How is life going to change? How will you pay for all of this? What if the treatment course doesn't work? What does the future hold? Is death a real possibility? You may feel as if your control has been stripped away. It's normal to feel helpless and overwhelmed. The best thing you can do is to talk about your fears. Discuss them with your family and friends, and with the members of your health care team. These people can assist you and gradually, you'll start to feel less helpless. Fears will come and go throughout the treatment process – it's an emotional roller coaster. Don't hesitate to reach out to those who can help you through difficult times.

Anger

Why is this happening to you and your family? Unfortunately, there are no answers to this question. It's just not fair, and you have every right to be angry. You may be angry at God or nature, angry at the medical profession, and you may even find yourself getting angry with the people around you. This is normal. But it's important to find healthy ways to vent your anger, because anger directed at other people can be destructive. Talk about your feelings with family, friends, members of your health care team, clergy or others facing similar circumstances. Cry. Exercise or work out. Write your feelings down in a journal. Join a support group. Meditate or do relaxation exercises. Listen to music. Go somewhere quiet and scream at the top of your lungs. Find an outlet that works for you.

Guilt

You may start to wonder if this disease came because you did something to cause or deserve it. You may reflect on your past and search for the actions or thoughts that may have made you "responsible" for bringing on the diagnosis. You might think you should have noticed the symptoms or gone to the doctor sooner. It's normal to feel guilty. However, nothing you did caused the illness. It's hard to accept the fact that the cause of the disease may forever remain unknown, but it's the truth. Once again, talking about your feelings is the best way to cope with them.

Grief

Most people associate the grieving process with death, but grief can occur whenever there is a sense of loss. When you or a loved one are diagnosed with a serious illness, you grieve the loss of good health, the loss of "normal life," and the loss of your hopes and dreams. Life has changed significantly, and in a direction that nobody would willingly choose. This can cause deep sadness. It's okay to grieve. Communicate your feelings, cry and let others comfort you. If grief seems to be taking over your life, though, talk to your health care team about professional assistance.

Hope

As people work through shock, anger, guilt, fear and grief, a sense of hope starts to grow. Hope is more than welcome – it's essential for the coping process. Hope is the mental energy that drives you to believe in a better tomorrow. It's okay to be hopeful, no matter what the circumstances are. Hope is flexible. For this reason, it's different than denial. Denial ignores reality, while hope changes to fit reality. A person can hope for a complete cure (and with the advancements in cancer treatment, this hope very often becomes a reality). If this isn't possible, that hope may change into the hope for comfortable, lasting remissions. And even if hope for survival is low, a person can hope for different goals, like the control of pain, the strength of family, or even a dignified ending. Whatever the case, hope is a driving force that keeps you going. It comes from within and can be fostered by the love and support of others.

While all of the feelings above are normal for people who are facing cancer or other serious illnesses, it's important to recognize the warning signs of depression.

According to the National Institute of Mental Health, if five or more of the following symptoms last for longer than two weeks, are not caused by medication, and disrupt usual functioning, it's important to be evaluated for clinical depression:

- Persistent sad or "empty" mood
- Loss of interest or pleasure in ordinary activities
- Fatigue or decreased energy
- Sleep disturbances (insomnia, early waking, oversleeping)
- Eating disturbances (lack of appetite or overeating)
- Difficulty concentrating, remembering, or making decisions
- Feelings of worthlessness
- Irritability
- Excessive crying
- Chronic aches and pains for no apparent reason
- Thoughts of suicide

If you think you or a loved one might be dealing with depression, talk to the members of your health care team to schedule an evaluation. Treatment is available and necessary. Studies show that depressed cancer patients experience more distress, more impaired functioning, and less ability to follow medical regimens. However, when cancer patients have their depression treated, they experience less suffering and enhanced quality of life. And when depressed caregivers are treated for their depression, they are better able to care for the patient and for themselves.

Common Emotional Responses – Child and Teen Patients

Children and teens who are diagnosed with cancer or pre-cancer may experience similar emotions to those outlined above – but they experience them at their own age levels. Listed below are some age-related feelings that child or teen patients may experience.

Be sure to speak with the social workers, child-life specialists and child psychologists on your health care team. They will be valuable resources for advice and assistance. And don't forget to refer to the lists of materials in CLF's Resource Room (found in the back pocket of this binder). We carry a number of educational materials that may be helpful for your family.

Infants

Of course, a baby can't understand what cancer is. They can recognize, however, feelings of physical discomfort, changes in routine and environment, and being separated from their parents – all of which may occur when an infant is receiving treatment for cancer. Your infant may express these feelings with behavior like crying or screaming, not holding still for medicine or tests, and clinging to you.

To help your baby cope at the treatment center, try to help them feel safe by being there to hold, touch and comfort them. Talk to your baby in soothing tones, and bring some of their comfort items (like a blanket, stuffed animal or pacifier) from home. Do your best to stick as closely as possible to your daily routines and rituals (regular nap, feeding and bathing times), and ask your health care team to cooperate with you as much as they can. And don't forget to take advantage of happy, quiet times.

Toddlers & Preschoolers

Toddlers have recently become accustomed to having a sense of control in their lives – they can manipulate objects, walk, use the toilet and generally have less dependence on mom and dad. Thus, when some of this control is stripped away with visits to the treatment center, they react with frustration and anger. Temper tantrums may increase. On top of this, they have a heightened fear of bodily harm. These factors may make it difficult for kids to hold still for tests and procedures.

Young children are also used to routines. When these routines are changed, your child may revert to behaviors recently outgrown (like thumb-sucking, baby talk or bed-wetting). This is their way of regaining security and feeling safe. As your child feels less stressed, these regression behaviors should decrease.

It's important to remember that preschoolers have vivid imaginations. If they are not told about their illness and its treatment, they can develop some scary misconceptions, including the belief that the illness and the treatment is punishment for previous bad behavior.

To help your toddler or preschooler cope, encourage them to talk about their feelings. Be sure to let your child know that cancer and its treatment did not come along because

anyone did anything that was wrong or bad. Be honest about upcoming procedures. It's important to clear up any misconceptions that may result from fear of the unknown, but don't feel the need to go into great detail too far in advance – this can create some anxiety. Your health care team may be able to help you explain cancer and treatment procedures in a way that young children will appreciate and understand.

Try to stick to your normal routine as much as possible – this includes praising and rewarding good behavior, and maintaining discipline when needed. Both help children feel secure. Allow your child to participate in normal activities to the extent possible. This may take some creativity. With some activities, you may have to discuss strategies in which your child can still enjoy participating, but in a slightly modified manner.

School-age Children

Children aged five to seven still worry that they became ill and have to receive unpleasant treatment because they did or thought something bad. They need to be reassured that cancer and the necessary treatment procedures are not punishment. As they get older, these fears diminish because children have a better understanding of illness and healing, and how the body works in general.

School age children are better able to process more detailed descriptions of upcoming procedures, but they still have a significant fear of bodily harm. They may get frustrated and act out because they struggle between wanting to be brave and independent and wanting to cling to their parents because they're "safe." It's important to be there to comfort and support your child, but it's also helpful to encourage them to take an active role in decision making and care activities when appropriate. This will help them regain a sense of control. Honest, open communication fosters this sense and an overall willingness to cooperate.

It's also important to allow your child to participate in regular activities with friends. This helps them feel "normal," which is important to self-esteem and self-identity. Feeling different at this age can be stressful. Instead, try to nurture a sense of "uniqueness."

Pre-teens & Teenagers

As they grow older, children become more and more analytical. Pre-teens and teens need information about their disease and its treatment. Many teens want to hear both the good and the bad news, and are particularly interested in their prognosis. They may even desire private meetings with members of the health care team. Information seeking should be encouraged, as should active participation in health-related decisions and self-care.

Teens feel invincible and indestructible. When they learn that they are facing a serious illness, their belief system is shaken. Some teens use denial as a coping mechanism. As mentioned earlier, some denial can be helpful. Avoiding the topic of cancer can be a necessary, temporary escape from trying and frightening times. But it's important to make sure denial doesn't ultimately interfere with your child's treatment or overall safety.

Teens also strive to be independent. When a teenager becomes a patient, his dependence on others automatically increases. There's also a struggle between wanting to be a brave adult and wanting to retreat into the safety and security of family. These internal conflicts can cause angry outbursts. Parents need to remember not to take these reactions too personally.

Pre-teens and teenagers are also very focused on their bodies and are sensitive to feeling "different." Physical side effects from cancer treatment (like hair loss or weight gain or loss) can have a significant effect on a teen's self-image. They may lack confidence and express a reluctance to interact with peers. On the other hand, teens have a strong desire for things to be "normal" again and peer interaction is a necessary ingredient in achieving that goal. As a parent, encourage open, honest communication about feelings, fears and frustrations. Teenagers may roll their eyes when reminded that physical changes don't change the person on the inside, but it's still important to say it. Your child may want to talk to you about these issues, but may prefer to handle them without your assistance. Simply remind your child, "If you feel like talking, I'm here to listen."

Interacting & Communicating with Others

Cancer affects relationships throughout all aspects of your life. Studies have shown that when people don't communicate about traumatic events, they are more likely to experience stress and its related health risks. Thus, we strongly encourage you to foster open communication with others so that together, you can better cope with cancer.

Family

At CLF, we refer to cancer as a "family disease." The patient experiences the medical struggles, but the entire family is affected. Family members can be a wonderful source of emotional support and practical assistance – in most cases, it's the support of family members that patients most cherish. However, family members must deal with the changing roles and routines that the diagnosis brings, and this is stressful. It's important to be aware of some of the strains that a family may experience when a serious illness is introduced.

- **Spouses of the Adult Patient/Parents of the Child Patient (Primary Caregivers)** – In addition to experiencing all of the emotions outlined above, primary caregivers have to adapt their roles within the family and take on additional responsibilities. This could include doing household chores that used to belong to the patient, earning extra wages outside the home in order to maintain financial stability, and taking care of the changing physical and emotional needs of children. The stress of these emotions and changing responsibilities can create feelings of anger and resentment, which can be misdirected at the patient. While it may seem like the caregiver is blaming the patient for the illness, what they are really resenting is how life is changing so dramatically.

It's of utmost importance to keep the communication lines open, especially between spouses. Sometimes, you'll both be feeling the same emotions, while other times, you'll be on different pages. Talk about how you're feeling and what your needs are, then discuss ways to help and support each other. Think about strategies for keeping your life as "normal" as possible, but be willing to adapt. And remember, you're not the first couple to experience these strains. You may find it helpful to talk to CLF or your

health care team about opportunities to interact with peers who have faced similar circumstances.

- **Children** – If young children aren't given honest explanations about what is happening with the person who is ill, they will draw their own conclusions. Young children worry that they may have done or thought something that caused the illness. They may also be worried that the disease is contagious – that they can catch it, like a common cold. Children and teens may resent how the illness has changed their routines. They may get angry because they suddenly have more responsibilities around the house, or because mom and dad are too busy or distracted to spend as much time with them as they used to. They may also be jealous of the extra attention that the ill parent or sibling is getting. These feelings may cause kids to “act up.”

Be honest with your children. Explain that the patient is sick, but that you and your health care team are doing everything you can to help them get better. Explain the diagnosis and treatment in terms that they can understand. Reassure them that cancer is not contagious and that nobody caused the cancer – it just happened, and nobody knows why. Get feelings out on the table. Encourage your children to share their thoughts and concerns, and be ready to share yours too. Work together to establish some realistic expectations. If the kids will have to help out around the house, explain why, and let them know how much you appreciate their help. If the illness or treatment side effects are going to prohibit you from participating in certain activities with your children, reassure them that you still love them, and discuss potential alternatives. For more information, refer to the Resource Room materials lists in the back of this packet. CLF carries some useful materials designed to help parents discuss cancer diagnoses with children. You'll also find it helpful to speak with your treatment center's social worker, and with other parents who have faced similar circumstances.

Friends

Friends are the people with whom you celebrate good times, and they're also the people on whom you hope you can depend during bad times. As you face a serious illness, many friends will handle it well – they'll always be prepared with open ears, helping hands and shoulders to cry on. However, despite the fact that they care about you and want you to recover, some friends will seem to fall short. You may find that these people start to drift away from you. There are a number of explanations for this type of behavior:

- **Fear of saying the wrong thing** – Some friends are so scared that they will say something that is inappropriate that they would rather avoid you than risk saying the wrong thing. In their minds, staying away prevents you from being hurt by their words, and it also prevents them from being embarrassed.
- **Being reminded of illness or death** – When someone close to you is diagnosed with a serious or life-threatening illness, it's a shock and a sudden realization that “this stuff really can happen.” Some friends will keep their distance because seeing or talking to you is a reminder that the world isn't perfect, and that they, too, could easily face similar circumstances.

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- **Fear of adding to your stress** – Friends know that you are facing many stresses. Some people will avoid you because they don't want to feel like "pests" during your difficult time.

One of the most common words that people use to describe how they feel when a friend is diagnosed with a serious illness is "helpless." No matter where your friends fall on the spectrum, they're looking to you and your family for guidance and direction. It doesn't seem fair that you should have to worry about other people, on top of worrying about yourself and your own family. But in the long run, if you can "ease the way" for friends, you and your family will benefit from their support.

So, make the first move. Reach out to your friends to let them know what is happening with you and what you need from them. Be honest about the diagnosis and treatment, about how you are feeling both physically and emotionally, and about what will and will not be helpful from friends. People won't know unless you tell them.

If you want people to call or visit, ask them to do so, and provide them with a list of convenient times. If you need some space for a while, ask friends to honor that wish, and let them know when you'll be in touch. If there are specific tasks with which you need help, provide friends with a list of concrete possibilities – this not only helps you get things accomplished, but it also makes friends feel less helpless. Try to provide as many specifics as possible, but let people know that your needs may change as time goes on. Assure them that you will keep them posted. Eventually, friends will need less and less guidance, and they'll be able to help and support you effectively without prompting.

Chances are, you simply won't have the time to sit down and chat with each friend or neighbor individually – especially at the beginning. But there are a couple of ways that you can get the word out to multiple people without running yourself into the ground. For example, e-mail is a wonderful tool. It allows you to compose a message the way you want it to read, and then with the click of a button, you can notify people near and far, all at once. It also provides people with an easy and immediate way to get back in touch with you. If you don't have e-mail, enlist a few friends and family members to be your communication helpers. Once you've given them detailed instructions about what you want them to say, give them lists of people to contact by email or phone.

Co-workers

Returning to work after being diagnosed with and/or treated for cancer can be rewarding (it can re-establish some normalcy in your life), but you'll have to be prepared for a variety of reactions from co-workers. These can range from avoidance to overprotection to bewilderment.

Once again, people need guidance, and you must be the one to provide it. Speak with your supervisor about strategies for communicating about your needs and concerns with your co-workers. Depending on your work environment and your own comfort level, a memo, an e-mail, a group meeting, or individual discussions may be the best way to express yourself and give others some hints for making the transition as smooth as possible.

If you will have some limitations, it's important that you discuss these with your supervisor and with others who may be affected. Together, you can establish a plan that can work for all involved.

And don't forget that you have legal rights. Under the Americans with Disabilities Act (ADA), employers with 15 or more employees cannot discriminate against workers with disabilities. This includes people with cancer. And under the Family and Medical Leave Act, the law requires companies with 50 or more employees to allow up to 12 weeks of unpaid leave each year for medical care (this covers both patients and family members caring for patients). For more information about the ADA, contact the Equal Employment Opportunities Commission (EEOC) at 800.669.4000 or online at <http://www.eeoc.gov>. For information about the Family and Medical Leave Act, contact the Department of Labor online at <http://www.dol.gov> or by checking the U.S. Government section of your local phone book. In both cases, the Wage and Hour Division can be of assistance.

Helpful Outlets

We've already discussed the importance of open communication and accepting help from others. There are a number of additional actions that people can take to help themselves cope with the emotional issues that surround a serious illness. Different things work for different people. A few suggestions are listed below. Try to be open to new ideas, but remember that you are the only one who knows what is and isn't helpful for you.

Keep a Journal

The simple act of putting words on paper can be therapeutic. It forces you to acknowledge your thoughts and feelings, and leaves you with a lasting document of them. As you read your own words, you learn more about yourself. And if you choose to share your words with others (some people do and some people don't), your journal can become a useful tool for starting discussions and helping friends and family members understand your world.

There are different ways to journal. Some people like to have some guidance or instruction before they write. However, many people prefer to keep their journals open-ended and just write about whatever happens to be on their minds at the moment. Do what feels best, but no matter what, be honest.

Below are some suggested ideas for guided journaling that you may find useful. If you prefer open-ended journaling, use the lined or blank note pages at the back of this binder, or start a notebook of your own.

- **Write about different emotions** – As humans, we experience a wide range of emotions. Complete the prompts below. Some of your answers may relate to the illness and its treatment, while others may be a broader expression of your life in general. As you read back over your answers, decide if there is anything that you can do, or that you can encourage others (friends, family members, your health care team, coworkers) to do in order to enhance or foster the positive feelings, and to reduce or eliminate the negative ones.

I feel hopeful when...

I feel frustrated when...

I feel excited when...

I feel afraid when...

I feel at peace when...

I feel guilty when...

I feel fulfilled when...

I feel angry when...

I feel happy when...

I feel sad when...

I feel needed/worthwhile when...

I feel discouraged when...

I feel relaxed when...

I feel confused when...

I feel like celebrating when...

- **Pick a theme** – Respond to the topics below. Do they spur any additional thoughts? Do any of your responses encourage you to take any action?

If I could talk to my cancer/pre-cancer face-to-face...

One of my fondest memories...

Five years from now...

I worry about...

If I could meet anyone in the world...

The thing that sets me apart from others...

One of the best pieces of advice I ever got...

My definition of support...

My definition of strength...

What I wish I could tell people, but for some reason, I don't...

It makes me laugh out loud when...

How I've changed...

What this disease can never change...

If I could make sure everybody knew one thing about me...

Practice Affirmations

Affirmations are positive statements designed to combat negative thinking. Many people feel that, by sitting in a quiet place, taking deep breaths and repeating these statements, you become more centered and you are able to keep your body and mind open to positive influences. You just sit back, relax and absorb the words as they are said.

Listed below are some affirmations for you to try.

- *I acknowledge all of my feelings as true and meaningful.*
- *I am a strong person.*
- *I trust in my body's ability to heal and in my mind's ability to cope.*
- *I will find something positive in my life each day.*
- *Delegating work is not a sign of weakness.*
- *I will let go of unrealistic expectations and demands on myself and others so I can concentrate on getting better.*
- *I willingly invite my family, friends and loved ones to lend me their support and strength.*
- *I am a beautiful, worthy person.*
- *I can see myself with a strong, healthy body – free of disease.*
- *I accept myself for who I am.*
- *I will forgive myself and others for errors of the past.*
- *I ask my body to work to rid itself of the disease and build new, healthy cells – and I know my body is listening.*
- *I know that I have many gifts to give and goals to accomplish, and I ask my body to cooperate.*
- *I feel my treatment working and I look forward to a bright and healthy future.*
- *I will beat this, and my family, friends and health care team will help me through it.*

Enjoy Simple Pleasures

As trying as times may seem, don't forget that certain actions bring you joy or help you relax. While they won't make the disease disappear, these activities will give you positive energy, which can only help you better cope with difficult circumstances. Identify the things that work for you, and commit to taking the time to enjoy them. Some suggestions are listed below. If you are unsure of the health effects of any activity, be sure to check with your health care team.

- Call, email or write to a friend or family member.
- Take a walk or ride a bike.
- Work in your garden, or take care of house plants.
- Record a CD of your favorite songs, or add a new playlist to your iPod.
- Read a book or magazine.
- Meditate.
- Prepare (or ask someone else to prepare) your favorite meal.
- Look through your photo albums and scrapbooks, or create a new one.
- Watch your favorite movie.
- Take a trip to a local museum, library, theater or zoo.
- Play with your pet.
- Organize a closet or junk drawer.
- Take a nap.
- Play on the internet.
- Take a long bath.
- Fly a kite.
- Make a list of your favorite things.
- Work on an art or craft project.
- Complete a crossword puzzle.
- Play a board or video game.
- Learn something new.
- Watch a sunrise or sunset.
- Ask people to write down their favorite jokes. Collect them all in one place so you always have somewhere to turn for a good laugh.
- Remember that CLF hosts a variety of recreation events to you for free. Check your email regularly so you don't miss out.

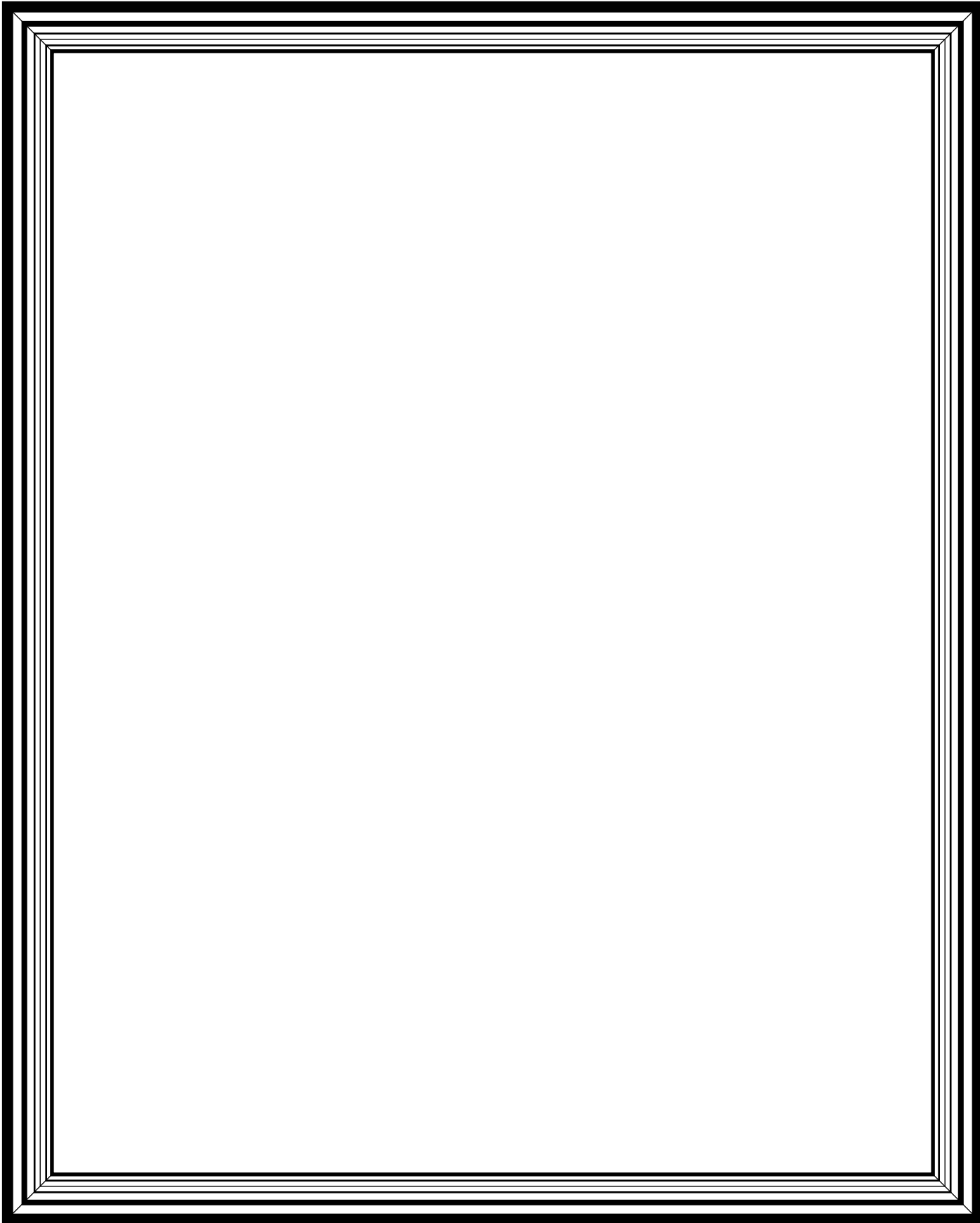
Draw!

The following pages contain some drawing exercises to help younger children express their feelings. These activities are most effective when you ask your child to explain the drawing to you. This opens the door to more in-depth discussions. Be sure to speak with your treatment center's social worker, child-life specialist or child psychologist for additional guidance.

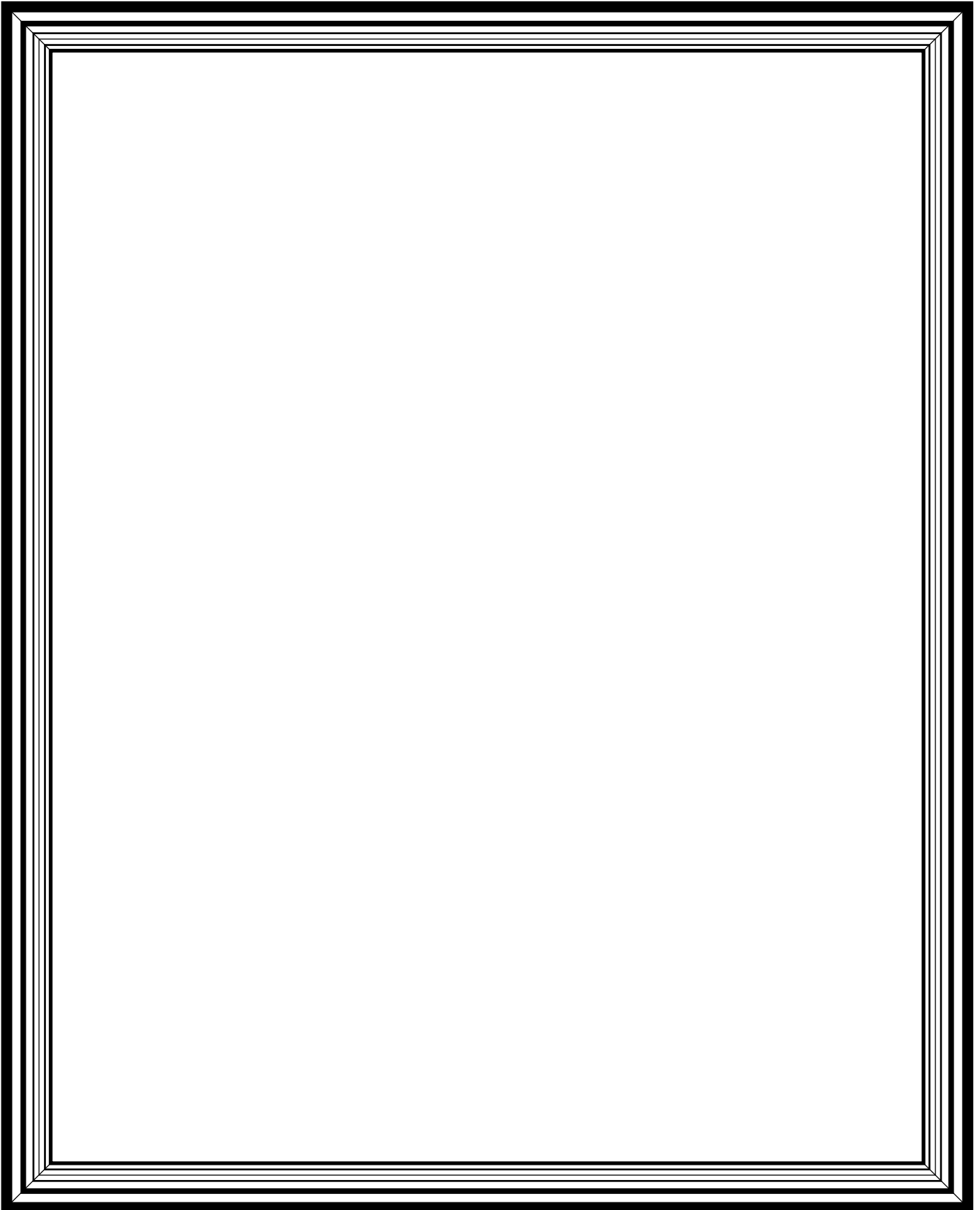
Pages:

- My Family and Me
- The Person Who Has Cancer
- How I Felt when I Found Out about Cancer
- The Health Care Team that works With My Family
- What Cancer Looks Like
- How Treatment Works
- Some of My Favorite Things
- What Bugs Me
- My Wishes for the Future
- A Blank Page

Me and My Family



The Person Who Has Cancer



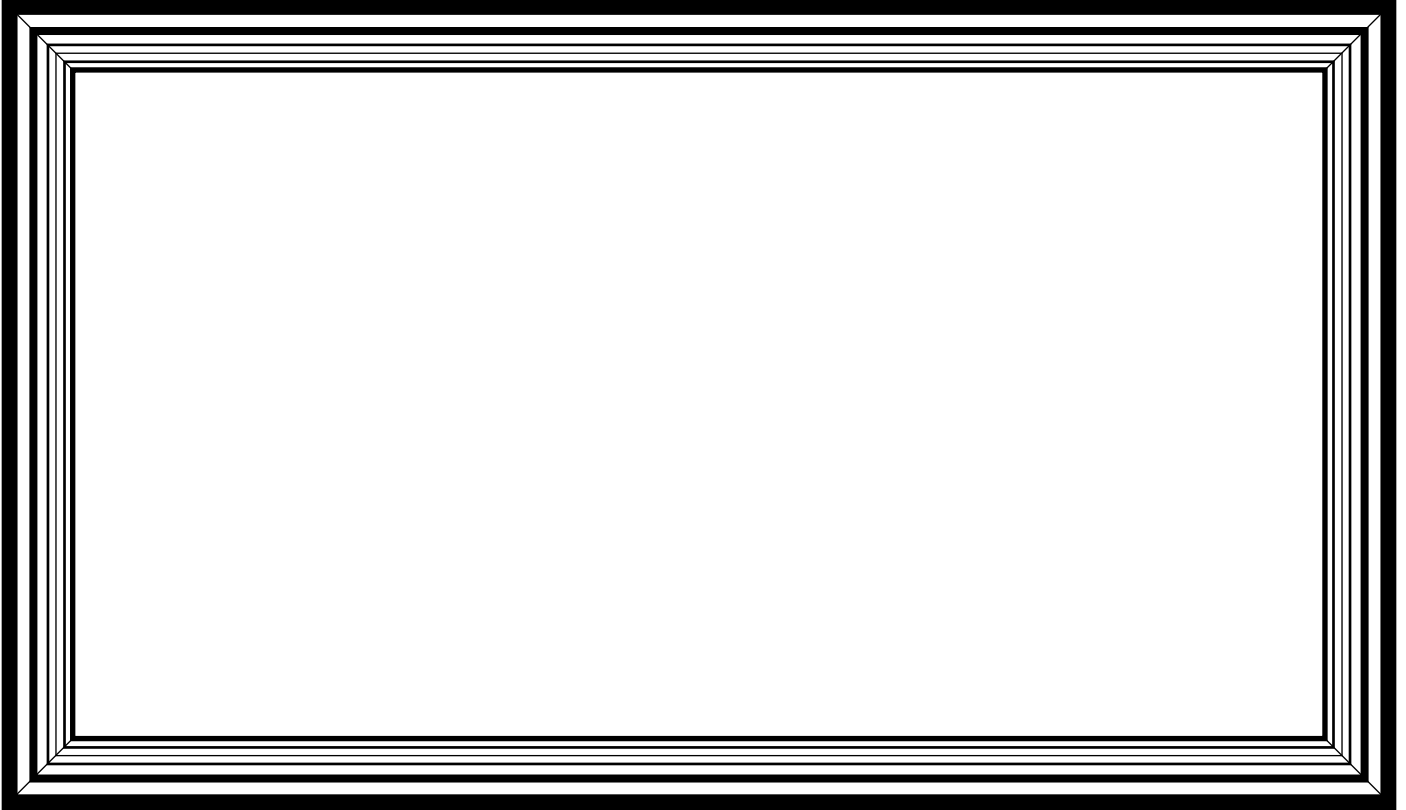
How I Felt when I Found Out about Cancer

A large, empty rectangular frame with a thick black border and multiple thin white lines inside, intended for a drawing or response.

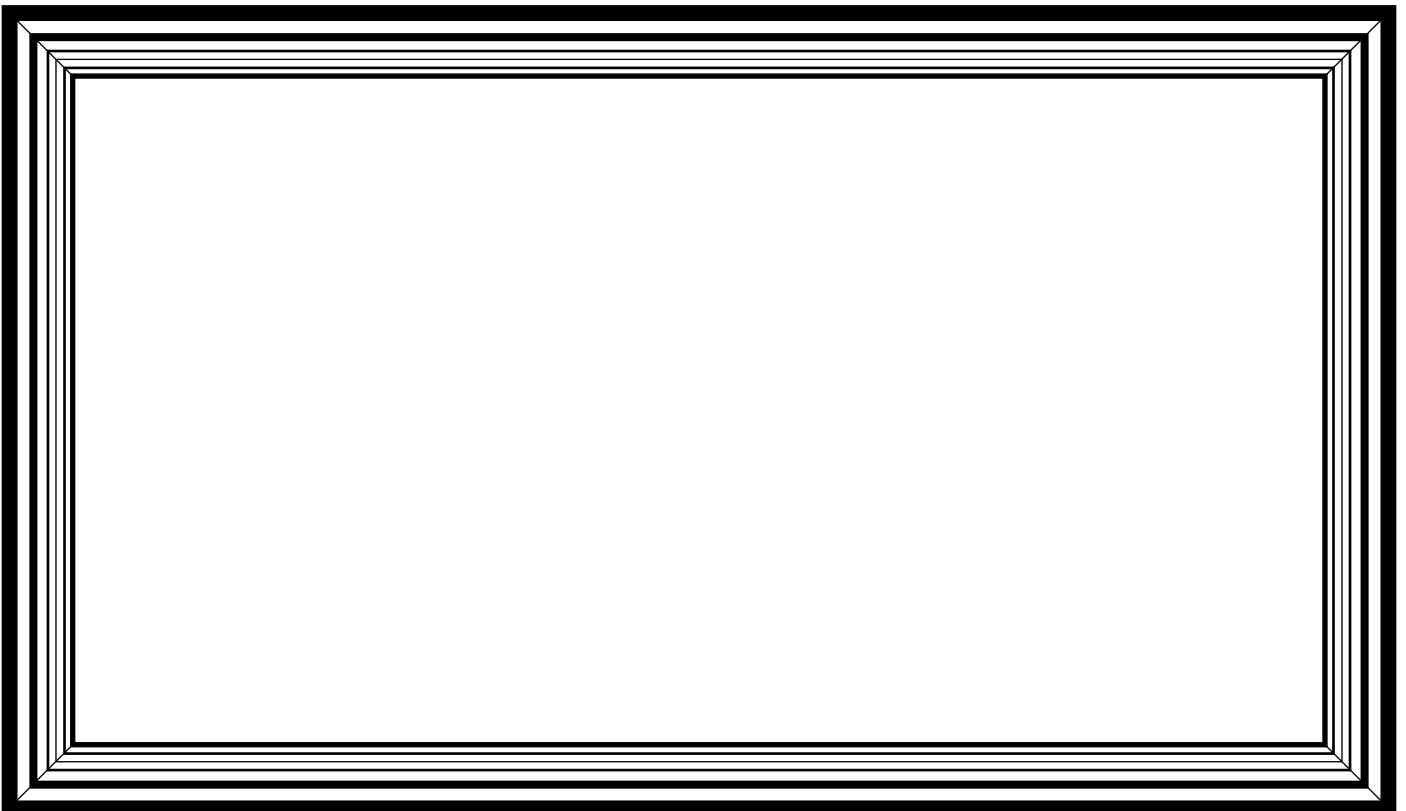
The Health Care Team that Works with My Family

A large, empty rectangular frame with a thick black border and multiple thin inner lines, intended for drawing or writing.

What Cancer Looks Like



How Treatment Works



Some of My Favorite Things

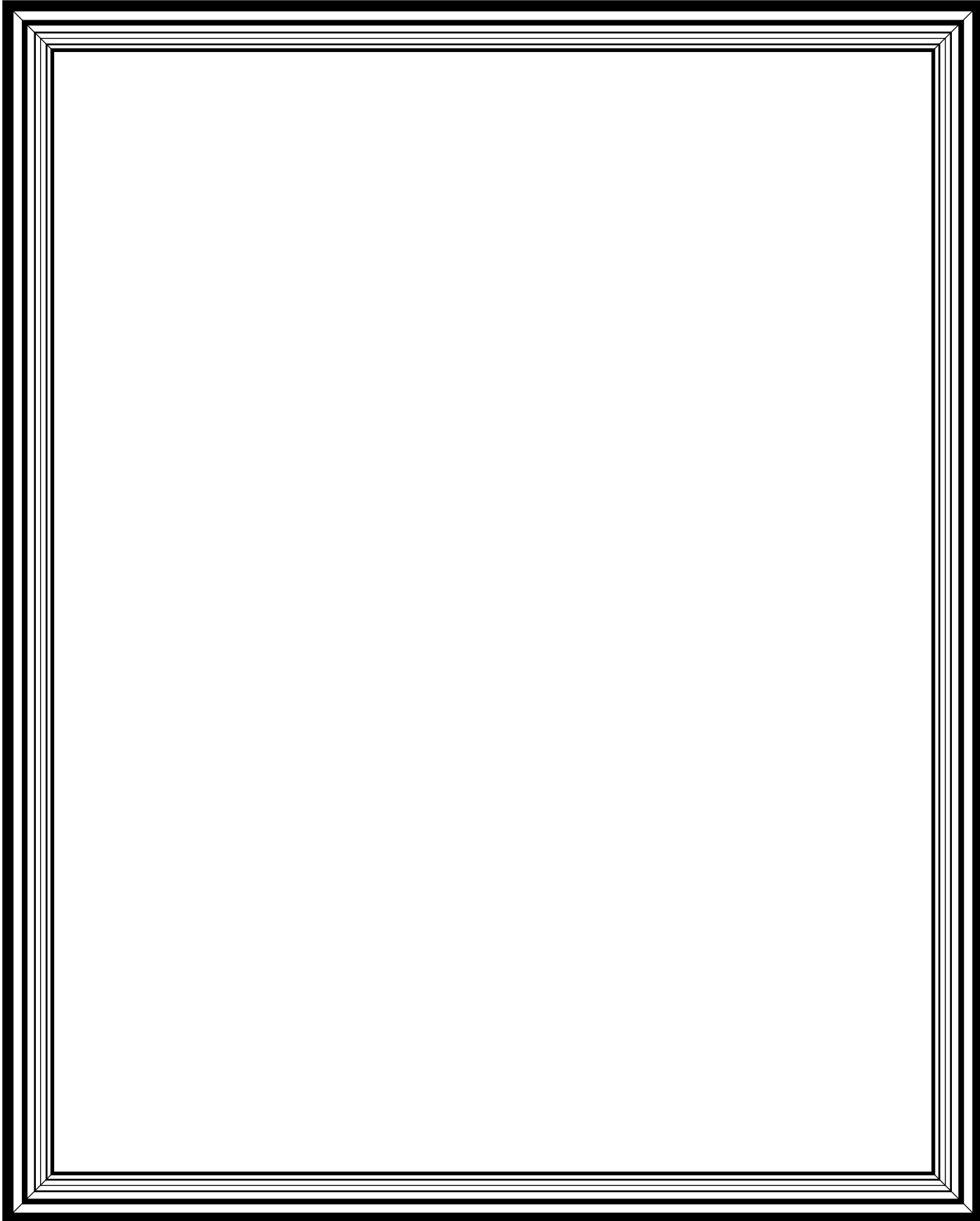
A large, empty rectangular frame with a thick black border and multiple thin white lines inside, intended for drawing or writing.

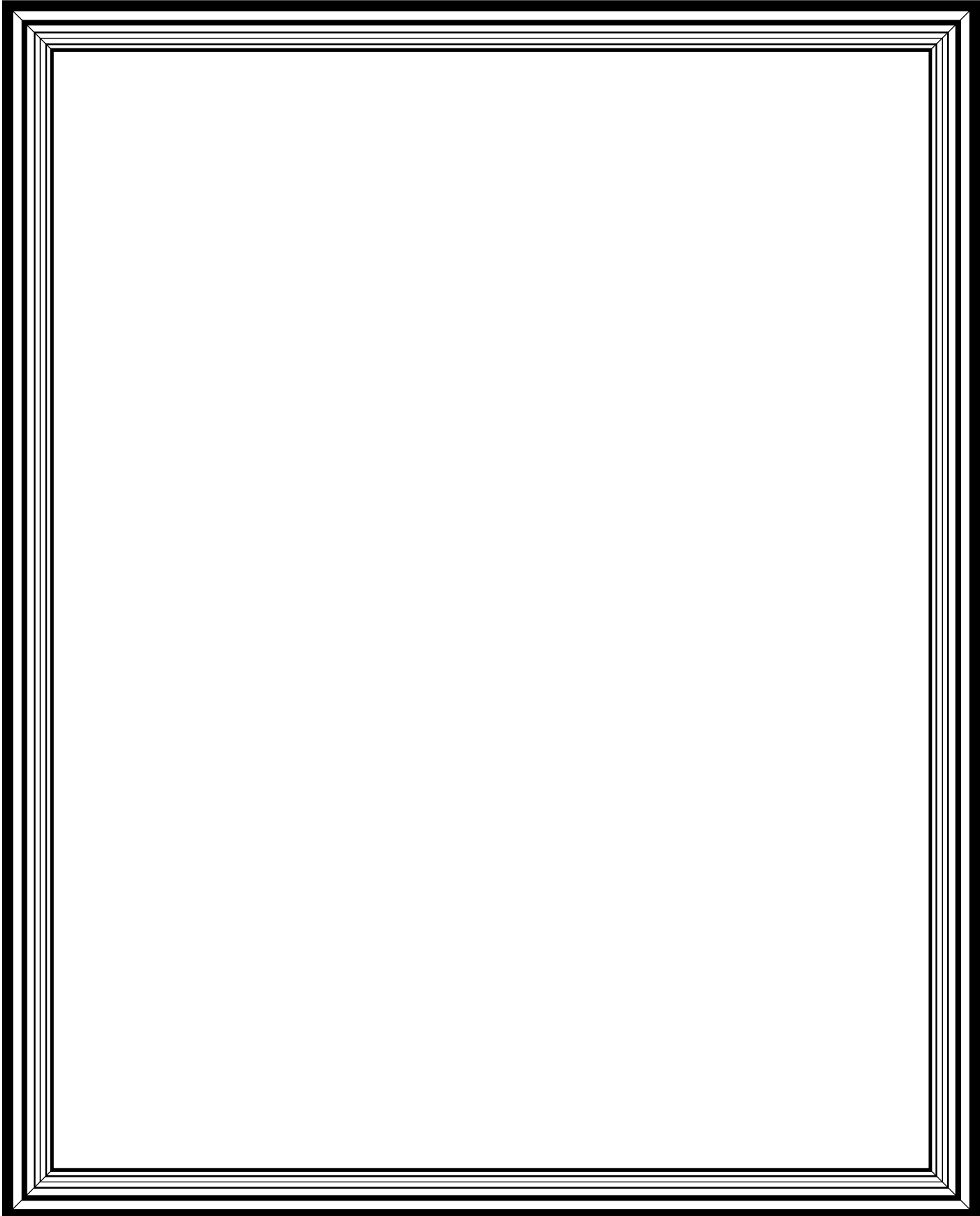
What Bugs Me

A large, empty rectangular box with a thick black border and a double-line inner border, intended for writing.

My Wishes for the Future

A large, empty rectangular frame with a thick black border and multiple thin white lines inside, intended for writing wishes for the future.





TAB NAME: "FINANCIAL ISSUES"

Financial Issues

While it may not be your initial concern, there is no escaping the fact that living with cancer, or any other serious illness, takes a toll on a family's finances. Medical care is very expensive. Even if you have health insurance, the premiums, deductibles, co-pays and other out-of-pocket costs quickly add up. And many expenses that go hand-in-hand with direct medical costs (like transportation to and from treatment and lodging for out of town treatment) simply aren't covered by insurance. Unfortunately, your everyday expenses like groceries, rent/mortgage, car payments and utility bills don't disappear when your family is facing difficult times. All of these costs must be covered – many times in the face of reduced wages.

These issues affect people of all income levels. Whether high medical costs actually affect your ability to meet your expenses, or they force you to make cut-backs that you didn't have to make in the past, or they simply shake your financial "peace of mind," they place a significant strain on your family.

That's why it's important to be aware of the resources available to help families cover medical costs and reduce financial burdens. Listed below are descriptions of different insurance options, benefit programs, and community resources. Additional sources of financial assistance are listed in Section 8, "Helpful Organizations." Combined, the information in these two sections will help you navigate the system and get assistance as needed.

It's not always easy. You can and probably will get frustrated. But don't give up. As frustrating as it is, the system still offers many solutions. CLF's Patient Services staff and your treatment center's social workers will do their best to help you through the process.

Most of all, please understand that it's okay to ask for help. If you've never had to do this before, it may seem strange or even uncomfortable. You may even feel like other people deserve assistance more than you do. CLF is here to let you know that, no matter what your situation is, if you're facing a serious illness, you have every right to seek out resources for financial assistance. Let these pages serve as your permission slip.

Various alternatives for meeting your financial needs are listed below. And don't forget to read the "Helpful Organizations" section. We encourage you to explore all of your options. If you don't have the time or energy, recruit a friend or family member to do so.

Fee-for-Service Health Insurance

Fee-for-service policies (also known as indemnity policies) are what most people think of as traditional health insurance. You pay a monthly or yearly premium, and the insurance company then pays a fee to your health care provider for each service you receive. You can choose your own doctors, specialists and treatment centers, as long as they accept your insurance. Fee-for-service policies have deductibles (the amount of money you pay before coverage starts). Once your deductible is met, the insurance company will cover a percentage (usually between 75 and 100 percent) of your medical expenses. You are responsible for paying any remaining expenses.

It's important that you understand your policy, especially when you or a family member are facing a serious illness. Carefully read through your policy holder's handbook, or talk to a customer service representative to find out which services are covered and with which limitations, which services are not covered at all, and how to appeal decisions if your claims are denied. Keep your policy and/or group number handy, and always keep records of any bills, payments, appeals or other interactions with your insurance company.

For more information, speak with your insurance company's customer service representative for information or complaints about your coverage. Your treatment center's social worker and billing department will also be able to help you handle insurance-related concerns.

Managed Care Organizations

Managed care organizations are health plans that establish a network of physicians, hospitals and other health care providers to care for people who enroll with the plan. These doctors and other providers agree to specific, negotiated rates in order to be included in the network. This, in turn, reduces costs for enrollees and for anyone else who helps pay for their health care (employers or the government, for example). Monthly premiums are usually lower than they are with traditional health insurance, and visits to the doctor or hospital usually only require a small (\$5 to \$20) co-payment, rather than a percentage of the service fee.

There are many types of managed care organizations, but health maintenance organizations (HMOs) are probably the most commonly recognized. If you are a member of an HMO, you are required to use doctors and hospitals under contract with the plan. You are also required to choose a primary care physician who will be in charge of coordinating your health care. If you need to see a specialist or go to the hospital, you must first get approval from your primary care physician (unless there is an emergency).

In a preferred provider organization (PPO), there is no primary care physician. If you choose to see a provider outside of the network, you'll have to pay a deductible, and if the charge for the services received exceeds the PPO payment rate, you'll be responsible for paying the rest out-of-pocket.

Point of service (POS) plans are also known as hybrid plans or open-ended HMOs. They're a combination of HMO and fee-for-service insurance. You're encouraged, but not required, to choose a primary care physician. You can also opt to go out of the network for services, but the POS will probably only cover 60 to 80 percent of the bill.

There are pros and cons to managed care. It's cheaper than fee-for-service insurance, but it's also more restrictive. It's very important that you understand your managed care plan, especially when you or a family member are facing a serious illness. Carefully read through your health plan membership booklet or talk to a customer service representative to find out which physicians and specialists belong to your plan, which services are covered and with which limitations, which services are not covered at all, and how to appeal decisions if coverage has been denied. Keep your group/plan number handy, and always keep records of any bills, payments, appeals/grievances, or other interactions with your managed care plan.

For more information, speak with your managed care plan's customer service representative for information or complaints about your coverage. Your treatment center's social worker and billing department will also be able to help you handle insurance-related concerns.

Medicaid

Medicaid is an assistance program that provides medical care for people with low income. The federal government sets basic program guidelines, and then each individual state administers its own Medicaid program within the federal guidelines. Both the state and federal government cover program costs. Medicaid usually pays for the full cost of inpatient and outpatient hospital visits, physician services, home care, prescription drugs, medical equipment/supplies, immunizations and some screening tests.

Pregnant women, single-parent families with young children, families in which the main wage-earner is not working, children and people with disabilities may qualify for Medicaid if their income and assets are below a certain level. In general, a person can receive Medicaid if they qualify for SSI (see the description under "Social Security Benefits"). Even though Medicaid has strict income limits, people with higher incomes may be able to receive assistance if they are judged "medically needy." In this case, the person is allowed to "spend down" to Medicaid eligibility by paying for a certain amount of their medical expenses to offset their excess income.

Many people now receive Medicaid benefits through a managed care program. This means that the patient must choose a primary care provider within the health plan. This physician then provides basic health care and must approve visits to other providers.

For more information, contact your treatment center's social worker, who can provide you with information about Medicaid and help you with the application process. For more information, contact Michigan's Medicaid hotline at 800.292.2550, or the Centers for Medicare & Medicaid Services online at <http://cms.hhs.gov>. You can also visit your nearest Family Independence Agency (FIA) office.

Medicare

Medicare is a federal health insurance program that is available for people age 65 and older and/or people with disabilities under the age of 65 who have been getting Social Security disability payments for more than two years (see the description under "Social Security Benefits"). Medicare coverage is divided into two parts: Part A and Part B. Part A is known as Medicare Hospital Insurance and covers expenses like inpatient hospital care, skilled nursing facility care, home health care and hospice care. Part B is known as Medicare Medical Insurance and covers physician and other outpatient services.

Co-pays and/or deductibles are required for services. Part A is premium-free (it's financed by a portion of your payroll tax/FICA), but Part B requires monthly premiums. People with low income and few resources may be able to have these costs covered by the state.

Medicare beneficiaries may now choose how they'll receive health care services. In the fee-for-service delivery system, a person can go to any doctor, specialist or hospital that accepts Medicare. The person must pay a fee each time they use a service, and prescription drugs are not covered. In the managed care delivery system, a person can only go to doctors, specialists or hospitals on the plan's list. However, costs may be lower than in the "fee-for-service" system, and some plans cover expenses like prescription drugs.

Supplemental coverage can be maintained or purchased to cover some of the health care costs not covered by Medicare. Supplemental insurance may come from an employer or union, from a former employer or union (if you're retired), or from a "Medigap" policy. Medigap is insurance that fills gaps in Medicare coverage. It comes from a private company, but must follow strict federal and state guidelines.

For more information, contact your treatment center's social worker, who can provide you with information about Medicare and help you with the application process. For more information, contact the government's official Medicare site online at www.medicare.gov or call 800.633.4227. You can also visit your nearest Social Security office.

COBRA

Before 1986, if a worker lost their job or changed employment, they would have also lost any health insurance benefits. This presented families with financial and medical concerns, especially if they were facing serious illness. COBRA (the Consolidated Omnibus Budget Reconciliation Act) now allows people to pay for continued health coverage for themselves and their families if they have lost their jobs, changed employment, or lost coverage because of reduced work hours. COBRA applies to any company with more than 20 employees and allows workers to continue coverage for up to 18 months or until they are covered under another program. And as of 1989, COBRA allows former employees to continue their insurance coverage up to the full 18 months if they switch jobs and their new insurance limits coverage for "pre-existing conditions." This is particularly helpful for families dealing with cancer.

For more information, speak with your personnel or human resources (HR) representative at work. Contact the Employee Benefits Security Administration at 866.275.7922 or online at <http://www.dol.gov/dol/topic/health-plans/cobra.htm> for print materials on COBRA.

Social Security Benefits

There are two disability programs available through Social Security: Social Security Disability (SSD) and Supplemental Security Income (SSI). These programs provide financial assistance to people affected by disabling conditions. While the guidelines for each program are different, the medical requirements are the same for both programs. An adult must have a physical and/or mental impairment that prevents them from working for a minimum of 12 months or is expected to result in the loss of life. A child must have a physical and/or mental impairment that keeps them from doing things children of the same age normally do. The condition must be expected to last at least 12 months or result in the loss of life. Cancer is a condition that may qualify a person for benefits.

SSD is available to workers (and their children or surviving spouses) who have accumulated Social Security credits during their working years – eligibility is related to prior payroll tax

(FICA) contributions. Monthly payments are determined based on previous lifetime earnings covered by Social Security. On the other hand, SSI is based strictly on financial need. It is not related to prior employment. Monthly benefits are adjusted according to the person's income. The disabled person is the only person eligible for benefits (family members cannot receive SSI benefits).

For more information, contact your treatment center's social worker, who will be able to answer some of your questions and help you with the application process. For more information, contact the Social Security Administration at 800.772.1213 or online at www.ssa.gov. You can also visit your nearest Social Security office.

The Hill-Burton Program

Hill-Burton is a federal government program that provides hospitals and nursing homes with funds for construction and modernization. In return, facilities that receive these funds are required by law to provide free or reduced charge care to people who cannot afford to pay. If you are receiving care at a Hill-Burton facility, and if your income falls near the current poverty guidelines, you may be eligible to receive services free or at a reduced rate.

For more information or for a list of Hill-Burton facilities, contact the Hill-Burton hotline at 800.638.0742 or the Health Resources and Services Administration online at <http://www.hrsa.gov/hillburton/default.htm>. Talk to your treatment center's social worker for details about the application process.

Viatical Settlements/Accelerated Benefits

Life insurance used to be considered a source of financial assistance only after a person had passed away. There are now two ways that terminally or chronically ill people can benefit from life insurance funds while they are still alive. One option is viatical settlement. This involves the sale of a life insurance policy to a viatical settlement company in exchange for a percentage of the policy's face value. The person receives a lump sum cash payment, which can be used at their discretion (for things like medical bills, mortgage or vacations). The amount of the settlement depends on a number of factors, including the patient's life expectancy and the cost of the policy's premiums.

Accelerated benefits (also known as living benefits) are another option. In this case, it's the life insurance company that pays the patient directly. For a transaction fee, the patient is rewarded a percentage (usually 25 to 75 percent) of the face value of the benefit early, while the rest is reserved as a death benefit. Percentages vary from company to company, and there are often some restrictions on how funds can be used. Accelerated benefits are included in some policies when they are sold, but often times, they are offered as riders or attachments to policies.

Benefits received before a person dies may be wholly or partially exempt from federal taxes. If receiving funds through viatical settlement or accelerated benefits, it is important to find out how it may affect your eligibility for other financial aid programs and if there are any tax implications.

For more information, talk to your financial advisor or a lawyer before you make any major decisions. For more information about viatical settlement or accelerated benefits, contact the Federal Trade Commission at 202.326.2222, or your life insurance provider.

Veterans Benefits

The U.S. Department of Veterans Affairs offers a wide range of benefits for people who have served in the U.S. armed forces. This includes assistance with health care provided through VA facilities, disability compensation, burial and memorial benefits and more. Health care benefits vary based on financial need. Dependents and survivors may also be eligible for some benefits.

For more information, contact the Department of Veterans Affairs at 800.827.1000 or online at <http://www.va.gov>.

Churches/Synagogues

Community outreach is an important focus for most religions. Churches, synagogues and other religious organizations sometimes have funds set aside to assist people with special needs, including medical costs and related expenses. In addition to direct financial assistance, many religious organizations operate food pantries, clothing programs and shelter services to help people meet their most basic needs. Clergy and office staff may also be able to provide people with referrals to other helpful community organizations. In many cases, a person does not have to be a member of the congregation to receive assistance. However, if you are a member, your own church or synagogue is probably is a great resource for various types of support.

For more information speak with clergy at your own church or synagogue, or check the yellow pages for listings in your community.

Community/Civic Groups & Service Clubs

Groups like Kiwanis, Lions Club, Rotary Clubs, Shriners, Masons and JayCees often help fund special projects for community members who are facing difficult times. Some groups may have specific guidelines for providing assistance, but many have quite a bit of flexibility to help with different needs. It's helpful to have a specific idea or strategy for assistance in mind when contacting these groups.

For more information, check with your local Chamber of Commerce or City Hall for a list of groups and clubs in your community.

Fundraising

Friends, family members, co-workers and members of the larger community often want to lend a hand when someone they know is facing a serious illness. Donating money is often the most convenient way for people to make a difference. By coordinating any type of fundraising effort, you can tap into people's desire to help, and provide them with a concrete method for doing so. Fundraising can take many shapes and forms, but it needs to be well thought out and well organized. You may consider coordinating a letter

writing campaign, or hosting a special event, or maybe even “piggy backing” on a well established event already sponsored by a church, civic group or school in your community. These are only a few examples. There are multiple fundraising websites you can set up, such as GoFundMe, YouCaring, or Crowdfunder. These sites typically take about 5% of your profits as an administrative fee.

If significant funds will be raised, you may want to consider setting up a trust account at a local bank. Named after the patient (“The Joe Smith Fund,” for example), this is a checking account that earns no interest. Funds raised are deposited into this account, and then checks can be written to cover the patient’s expenses. In most cases, contributions are considered gifts to the family (rather than income), so the family does not need to pay taxes on them. However, donors must be informed that their gifts are not tax-deductible. Donations are only considered tax deductible when made to a non-profit organization.

For more information or for assistance with fundraising ideas, check your local library or contact CLF at 800.825.2536 or online at info@leukemiamichigan.org – our Patient Services staff and Development staff may be able to work together to help you come up with some ideas. For information about trust accounts, contact your financial advisor and your bank. If you’re not satisfied with your own bank, check the yellow pages for a list of banks in your community.

Tax Deductions

Under the Internal Revenue Code, Section 213, some medical expenses for chronically ill family members are considered tax deductible. A person is considered chronically ill (for this purpose) if it has been certified by a licensed health care professional that they are unable to perform two activities of daily living (eating, toileting, transferring, bathing, dressing or continence) without substantial assistance for a period of at least 90 days. Of course, detailed records and receipts for medical expenses will be needed to support your claim.

For more information, contact your tax advisor, who will be able to help you determine if this or other tax laws may apply to your situation. For more information, contact the Michigan Department of Treasury’s Tax Help Service at 800.487.7000, or the IRS website at www.irs.gov.

Community Organizations/Non-profit Agencies

Don’t forget to refer to Section 8, “Helpful Organizations,” for the names of organizations that provide financial assistance.

Addresses, phone numbers and websites are provided for each organization. Contact CLF’s Patient Services department at 800.825.2536, or your treatment center’s social worker for more information.

TAB NAME: "CAREGIVER"

For the Caregiver

If your loved one has a chronic illness or disability, and you are providing emotional, practical or medical support, you are a family caregiver. As a family caregiver, you are different from a professional caregiver (like a doctor or nurse). Your decision to provide care and assistance comes from your sense of duty to your loved one and the relationship you have – it’s an emotional responsibility rather than a career requirement.

In the different sections of *Stepping Stones*, the word “you” is used often. In many instances, this word refers not only to patients, but also to caregivers. The information really applies to both groups. As a caregiver, you’ll need to know what the diagnosis means and which treatment options are available. You will be interacting with the health care team. You will help the patient cope with side effects. And you’ll deal with endless emotional and financial issues. In other words, you have needs, too!

This section has two purposes: First, to remind you that it’s important to care for yourself. Second, to give you some tools to help you manage and organize some of the basic tasks involved in caregiving. Please remember, though, that the rest of *Stepping Stones* is for you, too. We encourage you to take advantage of the whole kit.

Take Care of Yourself

When a family is dealing with cancer or another serious illness, people understand that the patient will face difficult times – frequent trips to the hospital, treatment side effects, worries about future health and survival, and more. What people often forget, though, is that these issues affect the caregivers as well. To add to this stress, caregivers must actually care for the patient, and complete the extra tasks that the patient can no longer handle. This can cause significant strains on a person’s health and overall well-being.

The information below is designed to remind you to take care of yourself. Not only do you deserve it, but if you look after yourself, you’ll be better able to help the patient, too.

10 Tips for Family Caregivers*

1. Choose to take charge of your life, and don’t let your loved one’s illness or disability always take center stage.
2. Remember to be good to yourself. Love, honor and value yourself. You’re doing a very hard job and you deserve some quality time, just for you.
3. Watch out for signs of depression, and don’t delay in getting professional help when you need it.
4. When people offer to help, accept the offer and suggest specific things that they can do.
5. Educate yourself about your loved one’s condition. Information is empowering.
6. There’s a difference between caring and doing. Be open to technologies and ideas that promote your loved one’s independence.

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7. Trust your instincts. Most of the time they'll lead you in the right direction.
 8. Grieve for your losses, and then allow yourself to dream new dreams.
 9. Stand up for your rights as a caregiver and a citizen.
 10. Seek support from other caregivers. There is great strength in knowing you are not alone.

* Reprinted from "10 Tips for Family Caregivers" with permission of the National Family Caregivers Association, Kensington, MD, the nation's only organization for all family caregivers. 1.800.896.3650; www.nfcacares.org

Seeking and Accepting Help

Just as we discussed in the "Financial Issues" section, it's okay to ask for help. And it's also okay to say, "Yes," when people ask you, "Is there anything I can do?"

One of the biggest misconceptions about seeking or accepting help is that it is a sign of weakness. In fact, it's a sign of empowerment. You are acknowledging that with the help of others, you can get more accomplished and sacrifice less of your own mental and physical strength. This, in turn, allows you to be a better helper.

The reality is that one person simply cannot do it alone. When you ask for help or accept it when it's offered, it's a win-win situation – the patient is cared for, you avoid burnout, and the people assisting you feel useful.

Whether you're asking for help or responding to an offer of assistance, it's best to be prepared with some specific tasks that will be meaningful and useful for you and the patient. Listed below are several suggestions for actions that people can take to help you. The latter part of this section also includes a "Help Chart" to help you keep these tasks and the corresponding helpers organized.

How can others help you and your family?

Practical assistance:

- Prepare a meal.
- Clean the house.
- Do the laundry.
- Go to the grocery store.
- Do some yard work/shovel snow.
- Be the babysitter.
- Transport children to their activities.
- Tutor children or help them with their homework.
- Assist with home repairs.

-
- Take care of the family pet.
 - Run errands as needed.
 - Help the family organize their finances.
 - Take the patient to doctor's appointments.
 - Pick up the patient's medications at the pharmacy.
 - Help attend to the patient's medical needs (with appropriate training).
 - Help the patient with activities of daily living (with appropriate training).

Remember, if people are helping with these tasks, you may have a chance to take a break and do something for yourself. Check Section 5, "Emotional Issues," for some simple pleasures you may be able to enjoy.

Emotional Support:

- Ask how things are going.
- Listen.
- Be there to celebrate good times or to lend a shoulder to cry on during bad times.
- Give hugs.
- Pray.
- Take you out for a chance to "escape" (to a restaurant, movie, comedy club, concert or park).
- Honor your family by sending a thoughtful card or gift, or making a donation to a worthy cause.

Keeping Organized

As you know, when you're caring for someone with a serious illness, keeping track of all of the details can really be overwhelming. As difficult as it may seem at first, it's important to try to keep as organized as possible.

The forms on the pages that follow are designed to help you get started. The more organized you are, the better prepared you will be to actually provide care, and the easier it will be to give others the guidance they need to help you.

The forms include:

- **Important Names and Numbers** – This is a place to list the family members, friends, health care professionals, community organizations and others important to the patient’s care and well-being. By completing it, you’ll have all of the important information in one place. And you’ll also have a helpful contact sheet to leave with anyone who may be helping to care for the patient in your absence.
- **Medication Information** – It’s important for everyone who helps with the patient’s medication to know about each drug and what it does. This sheet will help you keep track of that information.
- **At-a-Glance Medication Schedule** – Even after you’ve completed the Medication Information sheet, it’s still hard to keep track of which drug the patient should be taking and when. This chart will give you an at-a-glance view of the patient’s medication needs for each day of the week.
- **Help Chart** – As mentioned earlier, it’s good to be able to provide some specific ideas when you’re requesting or accepting help. This chart will help you take a look at your weekly needs, and then assign helpers as needed.
- **Month-at-a-Glance Planning Calendar** – These blank calendar pages can be used to chart a variety of items: Doctor’s appointments, important dates, treatment schedule – whatever will be helpful for you.

If you think these forms will be helpful, make several photocopies before you write in them – this is especially important for the weekly forms. Things change, so it’s best to be prepared with some blank sheets. You may also want to photocopy the forms once they are completed. That way, you can keep a copy in your *Stepping Stones* packet, but you can also post or distribute additional copies as needed.

Important Names & Numbers

Complete the following form to help keep important names and numbers organized. This will also be a helpful contact sheet to leave with anyone who is caring for/staying with the patient while the primary caregiver is absent.

Caregivers/Family Members

Primary Caregiver

Name		Relationship	
Phone	Home ()	Work	()
	Cell ()		
Address			
Email			

Supporting/Alternate Caregivers

Name		Relationship	
Phone	Home ()	Work	()
	Cell ()		
Address			
Email			

Name		Relationship	
Phone	Home ()	Work	()
	Cell ()		
Address			
Email			

Additional Family Contacts

Name		Relationship	
Phone	Home ()	Work	()
	Cell ()		
Address			
Email			

Name		Relationship	
Phone	Home ()	Work	()
	Cell ()		
Address			
Email			

Key Friends and Neighbors

Name		Relationship	
Phone	Home ()	Work	()
	Cell ()		
Address			
Email			

Name		Relationship	
Phone	Home ()	Work	()
	Cell ()		
Address			
Email			

Name		Relationship	
Phone	Home ()	Work	()
	Cell ()		
Address			
Email			

Health Care Needs

Primary Physician

(the doctor who coordinates/provides the majority of the patient's care)

Name	Specialty
Hospital/clinic	
Contact person (nurse/receptionist/secretary)	
Phone	Regular hours ()
	After hours/emergency ()
Address	
Email	

Other Physicians

Name	Specialty
Hospital/clinic	
Contact person (nurse/receptionist/secretary)	
Phone	Regular hours ()
	After hours/emergency ()
Address	
Email	

Name	Specialty
Hospital/clinic	
Contact person (nurse/receptionist/secretary)	
Phone	Regular hours ()
	After hours/emergency ()
Address	
Email	

Physicians (continued)

Name	Specialty
Hospital/clinic	
Contact person (nurse/receptionist/secretary)	
Phone	Regular hours ()
	After hours/emergency ()
Address	
Email	

Nurses

Name	Role in care
Hospital/clinic	
Phone	Regular hours ()
	Cell/voice mail ()
	After hours/emergency ()
Address	
Email	

Name	Role in care
Hospital/clinic	
Phone	Regular hours ()
	Cell/voice mail ()
	After hours/emergency ()
Address	
Email	

Name	Role in care
Hospital/clinic	
Phone	Regular hours ()
	Cell/voice mail ()
	After hours/emergency ()
Address	
Email	

Social Worker

Name		Role in care
Hospital/clinic		
Phone	Regular hours	()
	Cell/voice mail	()
	After hours/emergency	()
Address		
Email		

Pharmacy

Pharmacy name	
Contact person	
Phone ()	Hours
Address	
Is there a quick way to order meds/refills?	

Health Insurance

Company name	
Contact person	
Policy holder	Policy number
Phone ()	
Local address	

Medication Information

This form can be used in conjunction with the At-a-Glance Medication Schedule, also found in this section. For safety's sake, it's important for everyone who helps with the patient's medication to know about each drug and what it does. Record the data below. The pharmacy may also give you a printout that contains some of these facts. Try to keep all of this information in one place, like in the rings or pockets of this binder – you'll not only find it helpful for home care, but also for doctor's visits.

Drug	Color, shape, size
Dosage	On At-a-Glance Medication Schedule? Yes No
Start date	End date
Prescribing physician	Phone ()
What does this drug do?	
Potential side effects	
Potentially harmful drug interactions	

Record anything unusual that may have occurred as a result of taking this drug

Date	Problem
Date	Problem

Drug	Color, shape, size
Dosage	On At-a-Glance Medication Schedule? Yes No
Start date	End date
Prescribing physician	Phone ()
What does this drug do?	
Potential side effects	
Potentially harmful drug interactions	

Record anything unusual that may have occurred as a result of taking this drug

Date	Problem
Date	Problem

Medication Information

This form can be used in conjunction with the At-a-Glance Medication Schedule, also found in this section. For safety's sake, it's important for everyone who helps with the patient's medication to know about each drug and what it does. Record the data below. The pharmacy may also give you a printout that contains some of these facts. Try to keep all of this information in one place, like in the rings or pockets of this binder – you'll not only find it helpful for home care, but also for doctor's visits.

Drug	Color, shape, size
Dosage	On At-a-Glance Medication Schedule? Yes No
Start date	End date
Prescribing physician	Phone ()
What does this drug do?	
Potential side effects	
Potentially harmful drug interactions	

Record anything unusual that may have occurred as a result of taking this drug

Date	Problem
Date	Problem

Drug	Color, shape, size
Dosage	On At-a-Glance Medication Schedule? Yes No
Start date	End date
Prescribing physician	Phone ()
What does this drug do?	
Potential side effects	
Potentially harmful drug interactions	

Record anything unusual that may have occurred as a result of taking this drug

Date	Problem
Date	Problem

At-a-Glance Medication Schedule – Part 1

Week of _____

	Monday	Tuesday	Wednesday	Thursday
Morning	Drug	Drug	Drug	Drug
	Dosage	Dosage	Dosage	Dosage
	Time <input type="checkbox"/>	Time <input type="checkbox"/>	Time <input type="checkbox"/>	Time <input type="checkbox"/>
	Drug	Drug	Drug	Drug
	Dosage	Dosage	Dosage	Dosage
Afternoon	Time <input type="checkbox"/>	Time <input type="checkbox"/>	Time <input type="checkbox"/>	Time <input type="checkbox"/>
	Drug	Drug	Drug	Drug
	Dosage	Dosage	Dosage	Dosage
	Time <input type="checkbox"/>	Time <input type="checkbox"/>	Time <input type="checkbox"/>	Time <input type="checkbox"/>
	Drug	Drug	Drug	Drug
Evening	Dosage	Dosage	Dosage	Dosage
	Time <input type="checkbox"/>	Time <input type="checkbox"/>	Time <input type="checkbox"/>	Time <input type="checkbox"/>
	Drug	Drug	Drug	Drug
	Dosage	Dosage	Dosage	Dosage
	Time <input type="checkbox"/>	Time <input type="checkbox"/>	Time <input type="checkbox"/>	Time <input type="checkbox"/>
As Needed	Drug	Drug	Drug	Drug
	Dosage	Dosage	Dosage	Dosage
	Time <input type="checkbox"/>	Time <input type="checkbox"/>	Time <input type="checkbox"/>	Time <input type="checkbox"/>
	Drug	Drug	Drug	Drug
	Dosage	Dosage	Dosage	Dosage
	Time <input type="checkbox"/>	Time <input type="checkbox"/>	Time <input type="checkbox"/>	Time <input type="checkbox"/>

At-a-Glance Medication Schedule – Part 2

Week of _____

	Friday	Saturday	Sunday	Notes
Morning	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	
	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	
	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	
	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	
	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	
Afternoon	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	
	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	
Evening	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	
	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	
	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	
	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	
	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	
As Needed	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	
	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	

At-a-Glance Medication Schedule – Part 1

Week of _____

	Monday	Tuesday	Wednesday	Thursday
Morning	Drug	Drug	Drug	Drug
	Dosage	Dosage	Dosage	Dosage
	Time <input type="checkbox"/>	Time <input type="checkbox"/>	Time <input type="checkbox"/>	Time <input type="checkbox"/>
	Drug	Drug	Drug	Drug
	Dosage	Dosage	Dosage	Dosage
Afternoon	Time <input type="checkbox"/>	Time <input type="checkbox"/>	Time <input type="checkbox"/>	Time <input type="checkbox"/>
	Drug	Drug	Drug	Drug
	Dosage	Dosage	Dosage	Dosage
	Time <input type="checkbox"/>	Time <input type="checkbox"/>	Time <input type="checkbox"/>	Time <input type="checkbox"/>
	Drug	Drug	Drug	Drug
Evening	Dosage	Dosage	Dosage	Dosage
	Time <input type="checkbox"/>	Time <input type="checkbox"/>	Time <input type="checkbox"/>	Time <input type="checkbox"/>
	Drug	Drug	Drug	Drug
	Dosage	Dosage	Dosage	Dosage
	Time <input type="checkbox"/>	Time <input type="checkbox"/>	Time <input type="checkbox"/>	Time <input type="checkbox"/>
As Needed	Drug	Drug	Drug	Drug
	Dosage	Dosage	Dosage	Dosage
	Time <input type="checkbox"/>	Time <input type="checkbox"/>	Time <input type="checkbox"/>	Time <input type="checkbox"/>
	Drug	Drug	Drug	Drug
	Dosage	Dosage	Dosage	Dosage
	Time <input type="checkbox"/>	Time <input type="checkbox"/>	Time <input type="checkbox"/>	Time <input type="checkbox"/>

At-a-Glance Medication Schedule – Part 2

Week of _____

	Friday	Saturday	Sunday	Notes
Morning	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	
	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	
	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	
	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	
	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	
Afternoon	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	
	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	
Evening	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	
	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	
	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	
	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	
	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	
As Needed	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	
	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	Drug Dosage Time <input type="checkbox"/>	

Help Chart

Chart your needs so you're prepared to assign tasks.

Day & Date	Areas where help is needed/appreciated*	Time	Designated Helper	Notes
Monday /				
Tuesday /				
Wednesday /				
Thursday /				
Friday /				
Saturday /				
Sunday /				

* Areas where help is needed may include: Meals, doing dishes, cleaning house, laundry, grocery shopping, yard work, child care/babysitting, taking children to their activities, tutoring/help with homework, paying bills, administering medications, getting to doctor appointments, pharmacy pick-ups, home repairs, pet care, miscellaneous errands, recreational activities/giving family members a break, etc.

Help Chart

Chart your needs so you're prepared to assign tasks.

Day & Date	Areas where help is needed/appreciated*	Time	Designated Helper	Notes
Monday /				
Tuesday /				
Wednesday /				
Thursday /				
Friday /				
Saturday /				
Sunday /				

* Areas where help is needed may include: Meals, doing dishes, cleaning house, laundry, grocery shopping, yard work, child care/babysitting, taking children to their activities, tutoring/help with homework, paying bills, administering medications, getting to doctor appointments, pharmacy pick-ups, home repairs, pet care, miscellaneous errands, recreational activities/giving family members a break, etc.

Month-at-a-Glance Planning Calendar photocopy before first use

Month

Year

Sunday

Monday

Tuesday

Wednesday

Thursday

Friday

Saturday

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Month-at-a-Glance Planning Calendar photocopy before first use

Month

Year

Sunday

Monday

Tuesday

Wednesday

Thursday

Friday

Saturday

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TAB NAME: "ORGANIZATIONS"

Helpful Organizations

The following pages list organizations that specialize in services that help people cope with cancer and similar conditions. These organizations may be able to help your family with information, financial assistance or general support. Whenever you contact an organization, be sure to ask the following questions:

- What do I need to do to receive this service? Are there any eligibility requirements? Do you need any information or documentation from me? Do I need to complete an application?
- Do you know of any other organizations that can provide me with further assistance? How can I contact them?

Please note: There are many other community organizations that assist with general needs like food, clothing, housing, transportation, child care, chores and more. CLF serves the entire state of Michigan, so it is not possible to list each of these organizations here. If you need help locating these services in your community, please don't hesitate to contact our Patient Services department at 800.825.2536. We maintain an Information and Referral Database to help link you with the services you need.

Stepping Stones is reviewed on a regular basis. However, this type of information changes more frequently than *Stepping Stones* can be reprinted. If the contact information listed proves to be outdated and you are unable to find current data, please contact our Patient Services department at 800.825.2536 for assistance.

American Cancer Society

Great Lakes Division Office
1755 Abbey Road
East Lansing, MI 48823

Phone 800.ACS.2345 (call for a referral to the regional office nearest you)

Web www.cancer.org

Diagnoses covered Any cancer

- **Information** – Publishes a wide variety of educational materials (print and web). Provides referrals to useful organizations.
- **Financial assistance** – Varies by regional office. A few offices offer very limited direct assistance for help with medical expenses. Some offices offer a medical/adaptive equipment loan closet. ACS also sponsors a \$1,000 scholarship opportunity for cancer survivors attending Michigan or Indiana colleges or universities.
- **Support** – Varies by regional office. Some offer support groups and some offer the “Look Good, Feel Better” program to help women deal with illness and treatment-related changes in their appearance.

Aplastic Anemia & MDS International Foundation

100 Park Ave.
Suite 108
Rockville, MD 20850

Phone 800.747.2820

Web www.aamds.org

Diagnoses covered Aplastic anemia, myelodysplastic syndromes and other bone marrow failure diseases

- **Information** – Publishes a wide variety of educational materials (print and web). Provides referrals to useful organizations.
- **Financial Assistance** – Provides up to \$500 for travel expenses necessary for participation in a clinical trial.
- **Support** – Connects patients and families with peers who have faced similar circumstances through their “Network of Volunteers.”

Cancer Answer Line

Phone	800.865.1125
Web	www.mccancer.org/about/cancer-answerline
Diagnoses covered	Any cancer

- **Information** – Experienced oncology nurses from the University of Michigan’s Comprehensive Cancer Center respond to callers’ questions about cancer. Callers do not have to be patients at U of M.

Cancer Care, Inc.

275 Seventh Avenue, Floor 22
New York, NY 10001

Phone	800.813.4673
Web	www.cancercare.org
Diagnoses covered	Any cancer

- **Information** – Publishes a wide variety of educational materials (print and web) and a resource guide. Hosts educational teleconferences (free presentations on cancer issues via the phone lines).
- **Support** – Offers phone and internet support groups. Oncology social workers provide counseling services.

Cancer Information Service

(Phone Service Only)

Phone	800.4.CANCER (422.6237)
Diagnoses covered	Any cancer

- **Information** – Certified information specialists use a variety of printed and computerized resources to respond to callers’ questions about cancer. Information specialists also provide referrals to useful organizations. This service is supported by the National Cancer Institute.

American Childhood Cancer Organization

6868 Distribution Drive
Beltsville, MD 20705

Phone 855.858.2226

Web www.acco.org

Diagnoses covered Child and adult survivors of any childhood cancer

- **Information** – Publishes educational materials. Provides referrals to useful organizations.
- **Support** – Refers people to a variety of regional support groups. Helps people start support groups in their communities.

Children's Leukemia Foundation of Michigan

27240 Haggerty Road, Suite E-15
Farmington Hills, MI 48331

Phone 800.825.2536

Web www.leukemiamichigan.org

Diagnoses covered Leukemia, Hodgkin's disease, non-Hodgkin's lymphoma, multiple myeloma, aplastic anemia, myelodysplastic syndromes, myeloproliferative disorders, and any other malignant or potentially malignant disorder of the blood, bone marrow or lymphatic system. Services cover both child and adult patients and their families in Michigan.

- **Information** – Acts as a clearinghouse and lending library to provide people with print, video, audio and electronic information on a wide variety of cancer issues. Publishes a resource kit for registered families (*Stepping Stones*). Provides referrals to useful organizations.
- **Financial Assistance** – Provides reimbursement for treatment, prescription, travel, and wig or head covering costs through the traditional Financial Assistance Program. Operates a Special Needs Fund which provides one-time grants to help with costs that slip between the cracks of most other assistance programs (like rent/mortgage, family or post-BMT lodging, car repairs and child care). All funding subject to availability.
- **Support** – Connects newly diagnosed patients and families with peers who have faced similar circumstances through the Peer Support Network. Offers a variety of web-based support opportunities. Hosts recreation and holiday events and offers a Tickets Program to provide respite/"break" opportunities. Offers a Holiday Toys program to provide gift packages to child patients and their siblings, and the children of adult patients.

The Dream Foundation

1528 Chapala Street, Suite 304
Santa Barbara, CA 93101

Phone 805.564.2131

Web www.dreamfoundation.org

Diagnoses covered Adults facing the last 12 months of life

- **Support** – Grants wishes (vacations, family reunions) for adults (ages 18-65) who have been diagnosed with a terminal illness.

International Myeloma Foundation

12650 Riverside Dr., Suite 206
North Hollywood, CA 91607

Phone 800.452.2873

Web www.myeloma.org

Diagnoses covered Multiple myeloma

- **Information** – Publishes a wide variety of educational materials (print and web). Provides referrals to useful organizations.
- **Support** – Maintains a list of regional support groups and publishes the “Patient-to-Patient Directory.” Sponsors internet discussion groups.

Leukemia & Lymphoma Society

Michigan Chapter
1471 E. 12 Mile Road
Madison Heights, MI 48071

Phone 800.456.5413

Web www.LLS.org

Diagnoses covered Leukemia, Hodgkin's disease, non-Hodgkin's lymphoma, multiple myeloma, and myelodysplastic syndromes

- **Information** – Publishes a wide variety of educational materials (print and web). Provides referrals to useful organizations.
- **Financial Assistance** – Provides a limited amount of financial aid for qualified patients with a blood cancer diagnosis.
- **Support** – Offers a variety of support groups. Connects newly diagnosed patients and families with peers who have faced similar circumstances through their "First Connection Program."

Lymphoma Research Foundation

National Headquarters
115 Broadway, Suite 1301
Los Angeles, CA 90034

Phone 800.500.9976

Web www.lymphoma.org

Diagnoses covered Hodgkin's disease and non-Hodgkin's lymphoma

- **Information** – Publishes a wide variety of educational materials (print and web). Co-sponsors "Lymphoma & You" teleconferences. Provides referrals to useful organizations.
- **Financial Assistance** – Grants up to \$500. Number of grants awarded depends on funding available.
- **Support** – Connects patients and families with peers who have faced similar circumstances through their Lymphoma Support Network.

Mission of Hope Cancer Fund

209 E. Washington Ave.
Commonwealth Commerce Center, Suite 301B
Jackson, MI 49201

Phone 888.544.6423

Web www.cancerfund.org

Diagnoses covered Any cancer

- **Financial Assistance** – Assistance varies on a case-by-case basis. Helps with travel, prescriptions, medical equipment, maintaining insurance premiums, medical bills and out-of-town lodging.

My Friends Care Cancer Fund

148 Main Street, Suite 101
Mount Clemens, MI 48043

Phone 586.783.7390

Web www.myfriendscare.org

Diagnoses covered People facing bone marrow transplant

- **Financial Assistance** – Helps friends and family members organize a fund-raising support group for the patient. Members of this support group become volunteers for the organization, and the money they raise can go into an “account” for the patient’s BMT related costs (which has tax benefits). Provides no direct financial aid.

National Bone Marrow Transplant Link

20411 W. 12 Mile, Suite 108
Southfield, MI 48076

Phone 800.546.5268

Web www.nbmtlink.org

Diagnoses covered People facing bone marrow transplant

- **Information** – Publishes a variety of educational materials. Provides referrals to useful organizations.
- **Support** – Connects patients and families facing bone marrow transplant with peers who have faced similar circumstances.

National Coalition for Cancer Survivorship

1010 Wayne Ave., Suite 770
Silver Spring, MD 20910

Phone 888.650.9127

Web www.canceradvocacy.org

Diagnoses covered Any cancer

- **Information** – Publishes a wide variety of educational materials (print and web). Provides referrals to useful organizations. Helps families with advocacy issues (like health insurance and employment rights).
- **Support** – Maintains a list of regional support groups and helps people start new support groups in their own communities.

National Family Caregivers Association

10400 Connecticut Ave., Suite 500
Kensington, MD 20895

Phone 800.896.3650

Web www.nfcacares.org

Diagnoses covered Family caregivers of people facing chronic illness (including cancer/pre-cancer)

- **Information** – Publishes a wide variety of educational materials (print and web). Provides referrals to useful organizations. Some fees may apply.

National Foundation for Transplants

5350 Poplar Ave., Suite 430
Memphis, TN 38119

Phone 800.489.3863

Web www.transplants.org

Diagnoses covered People facing organ or tissue transplant, including bone marrow transplant

- **Financial Assistance** – Provides patients and family members with fund-raising expertise to help them cover BMT-related expenses.

National Leukemia Research Association (a.k.a. Children's Leukemia Research Association)

585 Stewart Avenue, Suite 18
Garden City, NY 11530

Phone 516.222.1944

Web www.childrensleukemia.org

Diagnoses covered Leukemia (services cover both child and adult patients)

- **Information** – Distributes educational materials and provides referrals to useful organizations.
- **Financial Assistance** – Assistance varies on a case-by-case basis. Helps with outpatient chemotherapy, radiation and other leukemia-fighting medications.

National Marrow Donor Program

3001 Broadway St. Northeast, Suite 100
Minneapolis, MN 55413

Phone 888.999.6743

Web www.marrow.org

Diagnoses covered People facing bone marrow/stem cell transplant, and those willing to be donors.

- **Information** – Maintains a registry of millions of people willing to be bone marrow/stem cell donors, and conducts searches to match patients with unrelated donors. Publishes a wide variety of educational materials (print and web). Provides referrals to useful organizations. Some fees apply.

National Organization for Rare Disorders (NORD)

55 Kenosia Avenue
PO Box 1968
Danbury, CT 06813

Phone 203.744.0100

Web www.rarediseases.org

Diagnoses covered Rare disorders (including rare cancers)

- **Information** – Publishes a wide variety of educational materials (print and web). Provides referrals to useful organizations. Some fees apply.

National Transplant Assistance Fund

150 N. Radnor Chester Road, Suite F-120
Radnor, PA 19087

Phone 800.642.8399

Web www.ntafund.org

Diagnoses covered People facing organ or tissue transplant, including bone marrow transplant

- **Financial Assistance** – Provides patients and family members with fundraising expertise to help them cover BMT-related expenses. Offers a Challenge Grant Program (awards \$1,000 after the first \$10,000 raised).

World Medical Relief

11745 Rosa Parks Blvd.
Detroit, MI 48206

Phone 313.866.5333

Web www.worldmedicalrelief.com

Diagnoses covered Various

- **Financial Assistance** – Provides donated medical supplies for people who cannot otherwise afford them. Durable medical equipment is available for people of all ages. Prescription drugs are available for seniors only. Provides no direct financial aid.

Useful Websites

As you can see, many of the organizations previously listed have websites that share useful information about the agency and/or about cancer and related issues. Don't forget to take a look at the websites mentioned on the previous pages. Listed below are some additional websites that you may find helpful. For easy access, visit CLF's website (www.leukemiamichigan.org) to be linked to many of the sites found on this page.

General Medical Information

These sites contain general medical information, and can be searched for information about specific diseases.

Healthfinder	www.healthfinder.gov
Healthology	www.healthology.com
Intelihealth	www.intelihealth.com
Mayo Clinic	www.MayoClinic.com
Medem	www.medem.com
U.S. National Library of Medicine	www.nlm.nih.gov

General Cancer Information

These sites contain general cancer information, and can be searched for information about specific types of cancer.

Association of Cancer Online Resources	www.acor.org
Cancereducation	www.cancereducation.com
Cancer.gov (Nat'l Cancer Institute)	www.cancer.gov
Oncolink	www.oncolink.com

TAB NAME: "WISDOM"

Words of Wisdom from Peers Who Have “Been There”

Information and support can come from a variety of sources – family, friends, your healthcare team and community groups. While this assistance can mean the world to you, support that comes from someone who has “been there” is special.

No two people are exactly the same, but families affected by cancer and its treatment have a common bond – a shared understanding of the feelings and concerns that accompany a serious illness. As you face uncertain times, simply knowing that others have been through what you’re going through can really make a difference.

The messages below are from patients and caregivers who have a special understanding of your situation, because they’ve faced it, too. These are the thoughts that would have been, were, or still are helpful as they cope with cancer. We all understand that there are no magic words to make it all better, but we do hope that some of these messages will be meaningful to you.

I have been three years in remission after seven weeks in the hospital where I underwent two chemo sessions. There will be some good days and many bad days. However, you must learn about your disease, learn to accept the love, comfort, and support of family and friends, and most of all, believe that you can and will be a survivor. You will not be alone. Reach out to those around you as they reach out to you.

— Mark,
a 45-year-old leukemia survivor

My words go out to the people who are involved in caring for and supporting the cancer patient. Try not to treat them any differently than normal. I think the most important thing in a cancer patient’s mind is to feel accepted and loved – just like it was another day! I know that I did not want people to feel sorry for me. All I wanted was to look to tomorrow and to live for the day.

— Michelle,
a 21-year-old non-Hodgkin’s lymphoma survivor

I was diagnosed in 1997 and finished chemo in '99. When it first came about, I remember how overwhelming it all was! Having lots of family and friends was my greatest support. My wife was by my side day and night. I had also done some research on the doctor we were referred to, so we felt very confident in his ability as my doctor. Having our faith in God also helped our family. Take it one day at a time and listen to and learn what is happening to you.

— Greg,
a 39-year-old leukemia survivor

Keep busy. Try not to feel too sorry for yourself. Do things you always wanted to do and don't procrastinate your life away. Don't put off for tomorrow what you can do today.

— Alan,
a 52-year-old Hodgkin's disease survivor

When I was first diagnosed, I felt as helpless and hopeless as I ever had in my life. Even though I am in medicine, I had no idea about what my diagnosis meant or what, if anything, could be done. I was fortunate that there was therapy available and within six months of my diagnosis I had a stem cell transplant. It was difficult for my family as well as myself, but things seemed to work out. I am now over two years cancer-free! I still wonder how long this will last. Will it come back next year? In five years? Never? But I'm beginning to realize that all that has happened to me, to any of us, has a 'purpose.' I don't know what it is, but my purpose has not yet been met. As time goes on, I try to focus less on myself, and more to that purpose. Gather family and friends around you. They want to help. Let them know how you feel and that you have hope – it will give them hope as well.

— David,
a 52-year-old non-Hodgkin's lymphoma survivor

These are the things that helped me most. First, never have negative thoughts. If I started to feel scared and think negatively, I just stopped and consciously pushed it out of my mind. Second, never ask, 'Why?'" Don't waste your energy on something you'll never hear the answer to. Third, open your heart to whomever. You will find even perfect strangers can feel your pain and sometimes their words or prayers can give you the strength you need to get through.

— Anita,
the parent of 25-year-old leukemia survivor

There is help available. Please use it. I did.

— Janet,
a 50-year-old non-Hodgkin's lymphoma survivor

A few of the most important words that come to mind are as follows. First, get support, whether it is family, friends, or someone who has been through a similar experience. Second, always try to keep a positive attitude. My positive attitude is a portion of the reason for being alive today. Third, communicate. Talk to people and let your feelings out – even if it's someone who found out about your situation, but you don't know very well. Talk to your doctor and be honest with him/her. Sometimes, you feel like all you do is complain, but you have that right! Believe it or not, doctors understand. Most doctors will do whatever possible to take care of your problems. I also got in contact with many others who experienced cancer and I learned a lot from these people that I wouldn't have otherwise known.

— Cate,
a 37-year-old leukemia survivor

What has helped me go through this difficult time is my friends and family. Just remember all of the wonderful things you have as you go through this hard time. Get better today so you can enjoy tomorrow.

— Trina,
a 32-year-old Hodgkin's disease survivor

My coping is done through the strength of my family. I have two beautiful grandchildren who keep me focused. I'm sure every day that someone tells you you can't give up. They're right, but you have to have your outlets – even if it's just crying, or being alone. Whatever keeps you sane. Whatever it is, do it. Your life is precious. Do whatever necessary to hold on to it. Cancer is generally a coward. Fight back. It helps.

— Diane,
a 49-year-old leukemia survivor

Through my experience, I've discovered that you have to live day-to-day, not in the past, and don't think about tomorrow. Think only of the day you're dealing with. Then the days pass faster and each day gets better. While you're going through treatment, the first couple of days aren't bad. Then think of it as, 'I'm half way through,' then 'I've only got three more days of this,' or whatever the case may be. Also, don't hold back pain, nausea, or any other symptoms you may have. Tell your doctor because they've got ways to treat almost all of the discomforts you may have.

— Linda,
a 42-year-old non-Hodgkin's lymphoma survivor

I learned that a positive attitude has a lot to do with healing and treatment. The poem 'Footprints' got me through the roughest times in my life.

— Susan,
the parent of a 15-year-old Hodgkin's disease survivor, and the spouse of a 41-year-old non-Hodgkin's lymphoma survivor

We (and I say 'we' because it affects your spouse and loved ones just as much as the patient) are 3 1/2 years into our fight with CML. Let people around you help you through this very difficult time. You can't do it alone. I have faced many difficult things in my recovery, and the support around you carries you on. You can win. It can be done, because I'm still here to tell you so.

— Ruth Ann,
a 58-year-old leukemia survivor

Believe that you will be cured! Have a positive attitude. Don't say or think that there is no chance of beating it. When you look into the mirror at yourself, don't say, 'Why me?' Say, 'Why not me?'

— Gary,
a 44-year-old non-Hodgkin's lymphoma survivor

I'm a single mom. I had just purchased a new house and before I moved in, I was diagnosed. I was blessed with my disease so that I could become a better person and a better mom. Now, three years later, I'm doing very well and I'm engaged to be married. I am a better person because I've learned patience, kindness, empathy, and what really is important in day to day living. Read everything you can get your hands on that is positive. Write a journal to express yourself – you may not always be able to tell people how you feel, or even want to. Don't get frustrated. Stress is like a poison. Believe in your doctors and believe in yourself. Don't be afraid to tell other people about your disease. You will be amazed at how others will be there to help and support you!

— Jill,
a 39-year-old Hodgkin's disease survivor

Here are a few lessons I learned as a result of my diagnosis and treatment. First, nothing is all bad – not even cancer! Of course my treatment was difficult, but the depth of my relationship with my wife changed in a positive way. Second, no bad situation is permanent. Whether the outcome is positive or not, you should rest assured that your cancer and its effect on you and your loved ones will resolve itself and everyone will eventually be at peace. Third, your response to cancer may be the best opportunity you'll ever have to teach others courage, understanding, and kindness. It can be seen as an opportunity to have a very positive and lasting impact!

— John,
a 42-year-old leukemia survivor

As a survivor of AML and a bone marrow transplant, I would encourage anyone experiencing the difficulties of both to believe that things can get better. At my lowest points, I didn't realize that there were better, easier, and more normal days ahead. Sometimes, when you're in the middle of the worst effects of cancer treatment, it's difficult to imagine yourself with improved health, especially if you've never been ill. Also, I would advise patients to accept that they are temporarily in a situation they can't control. It's okay to let those people who love you to now care for you and your needs, because they really want to. It also allows you to concentrate on doing all that's required for you to get better.

— Juanita,
a 48-year-old leukemia survivor

