

SARCOMA SURVIVOR STARTER NOTEBOOK

CREATED 2005 • UPDATED 2012



AMSCHWAND SARCOMA CANCER FOUNDATION
Offering love, hope, and tangible support



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Dear Patient, Caregiver, Family and Friends,

Let me start by thanking you for making the personal choice to triumph despite your or your loved one's diagnosis of sarcoma. Since our inception, the Amschwand Sarcoma Cancer Foundation has had the opportunity to serve many individuals who, like you, have waged personal war against this disease. Please know that you are not alone, even though a diagnosis of sarcoma can make you feel otherwise.

This year, close to 10,000 persons will be newly diagnosed with this rare form of cancer. Unlike persons with more common forms of cancer, sarcoma patients traditionally do not have the same benefit of knowing someone who has won the battle against this disease. As a result, a diagnosis of sarcoma can be isolating since it is often difficult to find others who share this experience and can exchange dialogue about the many challenges.

Fortunately, due to advances in technology and communication, the distances that have separated us from one another in the past no longer serve as barriers to our accessing critical resources that help us take a more proactive stance in the battle to conquer sarcoma. It is our hope that the Amschwand Sarcoma Cancer Foundation's *Sarcoma Survivor Starter Notebook* will be one such resource for you.

Developed by patients and caregivers with support from others who have joined us in the fight, it is our sincere hope that this notebook will provide you and your loved one with a jump-start toward becoming a Sarcoma Survivor. Written with contributions by other patients and caregivers, each section of the notebook begins with a brief description of its importance; however, the most important aspect of the notebook is its ability to be personalized. Because this is your battle, only you know what works best in terms of organizing your thoughts, records and all the other things that go along with a cancer diagnosis. By sharing what we've learned, it is our sincere wish to arm you with the tools necessary to get a head start so that you can focus on becoming well.

It is our privilege to assist you in this very personal journey. We thank you for allowing us to share our story and success.

Melissa Amschwand Bellinger
Executive Director



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The material provided in this document is for the sole use of patients and families of patient currently struggling with sarcoma, and other types of cancer. Its use for anything other than for, by or with patients is not allowed without express written consent of the Amschwand Sarcoma Cancer Foundation.

Requests for reproduction can be sent to:

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 Houston, Texas 77030



GETTING STARTED

What Is Sarcoma? Information for the Newly Diagnosed

Part of what makes a diagnosis of sarcoma so difficult to understand is that it can originate (or begin) in virtually any place in the body. Unlike other types of cancer that are named based on the site of origin, sarcoma cancers are differentiated from other forms of cancer in that they originate in connective tissue.

Malignant (cancerous) and rare, sarcomas originate in different connective tissues in the body, such as fat, blood vessels, nerves, bones, muscles, deep skin tissues, or cartilage. Each case of sarcoma can be very different in terms of how it initially presents which can make sarcomas difficult to diagnose since there is no standard set of presenting symptoms in patients.

Each year in the United States, there are approximately 9,800 new cases of soft tissue and bone sarcoma. While rare among adults (less than 2% of all adult cancers), sarcoma is one of the top five most commonly diagnosed cancers among children. It does not discriminate based on age, gender, race, or socioeconomic status. The outcome may be different for each individual based on his or her own unique set of circumstances.

Because sarcomas are rare, there is often insufficient data (or numbers of cases) to provide an accurate estimate of an individual's prognosis or chance of survival. Sarcoma type, staging, metastasis (whether it has spread beyond its primary or initial site), and treatment all play a role in the ultimate outcome. Since there are so many subgroups (or different forms of the disease), typically there are simply not sufficient numbers to say with certainty what one's individual prognosis will be. For this reason, a review of the statistics that are found online or in medical journals may be disheartening. If you choose to review the statistics, our recommendation is that you do so cautiously. Remember that first and foremost you are an individual. As such, no journal or statistic can predict your chance of survival. In fact, there are sarcoma survivors who have defied all odds, overcoming what at one point in time seemed to be an impossible challenge.

The rest of the information contained in this section goes into more detail to describe different forms of sarcoma. It is not an exhaustive list, but captures most subgroups. Also included is a handy compilation of suggestions for the newly diagnosed sarcoma patient.

We hope this information will be helpful to you in better understanding your disease. Perhaps the information will help you to better share information about your diagnosis with friends and family. How you use the information is up to you.



Sarcoma Definitions

There are many different forms of sarcoma. While not a comprehensive list, below you will find some of the most common subtypes:

Angiosarcoma — cancerous tumors originating from blood vessels.

Chondrosarcoma — cancerous tumors of cartilage.

Ewing's Sarcoma (also known as Peripheral Neuroectoderman Tumor or "PNET") — this form of sarcoma generally arises from very primitive cells in the body. It is usually classified as a bone tumor; however it can also originate in soft tissues in the body.

Fibrosarcoma — cancer that arises in the fibroblast-type cells (any cell from which connective tissue is developed) in the body. These cells form scars as well as perform other important connective functions. A sarcoma containing much connective tissue.

Gastrointestinal Stromal Tumor (GIST) — a form of cancer of the connective tissue that supports the gastrointestinal ("GI") tract. This form of sarcoma is also referred to as "GI Stromal Sarcoma."

Hemangiosarcoma — a cancerous tumor originating from blood vessels. Synonymous with Angiosarcoma.

Kaposi's Sarcoma — also known as multiple idiopathic hemorrhagic sarcoma— originates in multiple sites in the mid-dermis (second layer of skin) and extends to the epidermis (outer layer of skin). Some forms of KS look nodular or plaque-like on the skin. Lymphadenopathic form of KS is disseminated (scattered or distributed over a considerable area) and aggressive, involving lymph nodes, viscera, and occasionally the GI tract.

Leiomyosarcoma — cancerous tumors that originate in the smooth muscle tissue. (Smooth muscle is muscle over which the brain does not have conscious control. Examples include the muscles in the walls of blood vessels, the uterus and GI tract.) Leiomyosarcoma can originate anywhere in the body but the uterus or gastrointestinal tracts are the most common sites of origination.

Liposarcoma — cancerous tumors which arise from fat tissue. They can develop anywhere in the body, however they most often originate in the retroperitoneum (lining at the back of the abdominal cavity).

Lymphangiosarcoma — cancer that develops from the endothelial lining of the lymphatics.

Malignant fibrous histiocytoma (MFH) — an often times controversial form of sarcoma due to its uncertain histogenesis and numerous subtypes. Still this form of sarcoma is perhaps the most common form of common soft tissue sarcoma (accounting for 20-24% of soft tissue sarcomas) diagnosed in late adult life.

Malignant Peripheral Nerve Sheath Tumor (MPNST) — a cancer of the cells that surround the nerves. This form of cancer is also often referred to as neurofibrosarcoma.

Neurofibrosarcoma — a cancer of the cells that surround the nerves. This form of cancer is often referred to as Malignant Peripheral Nerve Sheath Tumor (MPNST).



Osteogenic sarcoma — a form of cancer that arises in bone. This form of sarcoma is also known as osteosarcoma.

Osteosarcoma — a form of cancer that arises in bone. This form of sarcoma is also known as osteogenic sarcoma.

Peripheral Neuroectodermal Tumor of “PNET” (also known as Ewing’s Sarcoma) — this form of sarcoma generally arises from very primitive cells in the body. It is usually classified as a bone tumor; however it can also originate in soft tissues in the body.

Rhabdomyosarcoma — cancerous tumors that originates in muscle tissue. These tumors are most common in the arms or legs, but can also develop in the head, neck, heart, urinary, or reproductive organ areas. This is one of the most common forms of sarcoma diagnosed among children.

Synovial Sarcoma — this form of sarcoma is comprised of cells that resemble the cells in joints. While synovial cells normally line the joints of the body, synovial sarcoma does not necessarily arise in any joint. The name of this particular form of sarcoma is probably a misnomer, since the cancer cells in synovial sarcoma are likely to be very different from normal joint cells. Synovial sarcomas can originate in any location in the body. It often appears in young adults.



Recommendations for the Newly Diagnosed Sarcoma Patient

Suggestions for those newly diagnosed with sarcoma cancer include but are not limited to the following:

- 1) Join the Association of Cancer Online Resources (ACOR) sarcoma list serve and open up dialogue with other sarcoma patients, survivors, and family members concerning treatment options, diagnosis, helpful advice, and emotional support. Participation on the list is helpful and at no cost to you. If you are unable to join the list, ask a trusted friend to do so on your behalf. (www.acor.org)
- 2) Research doctors, hospitals, and targeted cancer centers. Seek an opinion from a sarcoma center or doctor who has considerable experience treating sarcoma cancers. Sarcoma can be very different from other cancers in how it responds to treatment. Therefore it is wise to seek the opinion of someone who is experienced in treating this specific form of cancer. Many well-qualified and highly seasoned oncologists have never had a patient with a diagnosis of sarcoma. Do not assume that your doctor knows sarcoma. Ask him or her how many sarcoma patients s/he has treated throughout his/her practice and within the last year.
- 3) If a sarcoma specialist is not available in your area and travel is out of the question, ask your doctor to consult with a sarcoma specialist elsewhere. Often times, treatment can be administered by your hometown oncologist with follow-up and direction being offered from a sarcoma center. See the ASCF list of sarcoma centers (www.sarcomacancer.org) available in the United States.
- 4) Find a personal advocate or someone whom you trust to carry out your wishes and provide emotional support for you throughout your treatment. This can be a friend, loved one, or co-worker. It is also strongly suggested that if possible this person be willing to act as your medical advocate or defender in the event you are unable to strongly make your own case. Share your feelings with this person. If you are ill or upset, it can be helpful to have someone with you during meetings with your doctor to remember exactly what was said. Having this person serve as your “secretary” (by taking notes during meetings with your health care providers) can help you make sure valuable information is not lost.
- 5) Join a local support group. Many of the sarcoma centers have sarcoma specific support groups. If you do seek treatment in or live in any of these areas, look into other more general cancer support groups in your community. Also, do not minimize the impact that an online support group may offer (especially for people in rural areas). There are also special support groups for loved ones and parents of children with sarcoma.
- 6) Prepare a written list of questions for your doctor or nurse prior to each meeting. It can be difficult to remember each question when emotions run high or after receiving news about your treatment’s progress. Write all medical appointments on a calendar along with your treatment schedule and a list of all the medications you are taking (and the dosage) and keep this with your list of questions. Bring it to all of your appointments. This will make it easier to refer back to information, if necessary, when talking with your doctor or nurse.



- 7) Do not be intimidated or afraid to ask anything. Your doctor and the others on your health care team work for you. And you have a right to fully understand all of your treatment options and any potential side effects associated with your choices.
- 8) Ask for clarification on any tests or procedures that you do not understand. “Are they necessary?” “How can they help you?”
- 9) Get copies of your x-rays, scans, or test results. Store them in a safe place so that you can refer back to them, if necessary, or bring them with you to seek a second opinion.
- 10) Do not assume that no news is good news. Learn about your own health condition and treatment by asking your doctor and nurse and using other reliable sources.
- 11) Share the Amschwand Sarcoma Cancer Foundation web site, and others that you find to be helpful, with your physician.
- 12) Remain involved and proactive in your treatment. Research shows that involved and engaged patients often feel better than those who take a more passive role.
- 13) Research cancer-fighting diets and optional minerals and/or supplements. Talk about these options with your doctor or a dietician.
- 14) Read relevant books: medical, science, support, inspirational, religious, spiritual, complementary (mind/body), informational, and dietary. See the ASCF sarcoma patient recommended reading list on our website (www.sarcomacancer.org).
- 15) Use caution when seeking health information. While the Internet and library can be helpful sources of information, not all resources found will be accurate. Look for books, websites and other resources endorsed or recommended by qualified professionals. If in question, ask your doctor, nurse, or social work for an opinion.
- 16) Remember that you have choices. You have the right to choose your doctor, hospital, and course of treatment.



BEING PROACTIVE

Being a Proactive Patient (Means Asking Questions)

A proactive patient is one who has dedicated himself/herself to surviving sarcoma. You may have many questions regarding sarcoma and your treatment. In order to get the most out of your appointments, this section suggests ways to: prepare yourself for each health visit, establish a rapport with your healthcare team, and develop a system or identify a person to assist you in taking notes.

Be prepared. If possible before your appointment, do some research or have a loved one do it for you. The more educated you are, the better questions you will be able to ask. This will also show your physician that you are committed to learning as much as you can about your disease and its treatment. In the Resources section of your *Sarcoma Survivor Starter Notebook*, you will find resources to aid your learning process.

Establish rapport. It is important from the onset to establish a positive relationship with your physician and healthcare team. Keep in mind, good teams communicate well. As such, your doctor will have questions for you and likewise you will have questions for him/her too. This is a part of having a healthy rapport.

It is important to note however that while your doctor inherently wants to answer your questions, s/he likely has time restraints and limitations too. As such, focus your questions and start with the most important first. Remember that each member of the healthcare team may be a resource for different topics. While you have a right to have all of your questions answered, numerous or repetitive questions might irritate some doctors. Keep in mind your doctor has many patients who need of his/her time and attention. As such, it is necessary to find a good balance.

Also remember that each doctor has a different style. If one style does not work for you after a few encounters, you may consider changing to a doctor whose communication style is more in line with your own. Once you find a good fit, make yourself known as a person to your doctor, not just a patient. Show them a photograph of your children, parents, siblings, nieces, nephews, or pets. Introduce them to your caregivers.

Take notes. The following pages will be helpful for the patient to write down questions, responses, and notes. Make sure to include dates on all entries and the name of the physician and nurse answering the questions. This will make up an important history to which you can refer later.

Bring a support person. Sometimes it can be difficult trying to listen, ask questions and take notes all at the same time. This can be particularly difficult during a stressful visit with the doctor. As such, consider bringing a trusted friend, family member or other support person to your appointments. This person can assist you in taking notes, remembering what questions you want to ask and recapping the information provided by the doctor after your visit. Make sure this person knows in advance what his/her role will be during each visit.



Physician/Nurse Encounter Log

DATE	QUESTION	RESPONSE	PHYSICIAN/NURSE



Physician/Nurse Encounter Log

DATE	QUESTION	RESPONSE	PHYSICIAN/NURSE



Physician/Nurse Encounter Log

DATE	QUESTION	RESPONSE	PHYSICIAN/NURSE



MEDICAL HISTORY

You will often be asked to recount your medical history. After writing your history, make numerous copies and keep them in your notebook.

Important information which should be included:

- Childhood illnesses
- Traumas and injuries (broken bones, car wrecks)
- History of medication use and any allergic reactions
- Onset of menstrual period, menopause, or pre/post menopause
- Allergies
- Your family's medical history (illnesses of your blood relatives)



MEDICINES & COMPLIMENTARY THERAPIES

It is imperative that you keep detailed records of your medicines and complimentary therapies, including vitamins, supplements and herbs. High dosages of certain vitamins may have an adverse reaction when taken with certain medications. In addition, certain medications should not be taken together. A detailed record may assist physicians and pharmacists in devising your treatment plan.

The following log sheet will assist you in organizing your medications. It may also be helpful to keep the pharmacy disclaimers and prescription information along with the log sheet in your notebook for future easy reference should you, your loved one or your healthcare team need the information later. A sheet protector has been provided for this purpose.



Pharmacy Information Log

Name: _____

Name: _____

Phone: _____

Phone: _____

Medicines & Complimentary Therapies

Name (Generic Brand)	Dosages	Used For	Prescription Number



CONTACT INFORMATION

Your contact information is one of the most useful sections of your notebook, and it is important to keep it readily available. The sheets following include suggested contacts but you may also want to include personal contacts such as: utilities, banks, childcare providers, schools, babysitter, spouse's work, parent's work, etc. Plastic business card organizers have also been included to keep track of those business cards you have for the various members of your care team.

Make sure you keep detailed notes of your conversations, including the date and name of the person with whom you spoke. Do not hesitate to ask them to explain or spell information you do not understand.



Important Contact Information

Emergencies

Name:	_____	Name:	_____
Address:	_____	Address:	_____
City/St/Zip:	_____	City/St/Zip:	_____
Home:	_____	Home:	_____
Cell:	_____	Cell:	_____
Work:	_____	Work:	_____
Fax:	_____	Fax:	_____
Email:	_____	Email:	_____

Doctors

Name:	_____	Name:	_____
Hospital:	_____	Hospital:	_____
Phone:	_____	Phone:	_____
Fax:	_____	Fax:	_____
Comment:	_____	Comment:	_____
Name:	_____	Name:	_____
Hospital:	_____	Hospital:	_____
Phone:	_____	Phone:	_____
Fax:	_____	Fax:	_____
Comment:	_____	Comment:	_____

Nurses

Name:	_____	Name:	_____
Hospital:	_____	Hospital:	_____
Phone:	_____	Phone:	_____
Fax:	_____	Fax:	_____
Comment:	_____	Comment:	_____



Insurance Company

Contact Name:	_____	Contact Name:	_____
Company:	_____	Company:	_____
Policy #:	_____	Policy #:	_____
Address:	_____	Address:	_____
City/St/Zip:	_____	City/St/Zip:	_____
Phone:	_____	Phone:	_____
Fax:	_____	Fax:	_____
Email:	_____	Email:	_____
Website:	_____	Website:	_____

Social Workers

Contact Name:	_____	Contact Name:	_____
Address:	_____	Address:	_____
City/St/Zip:	_____	City/St/Zip:	_____
Phone:	_____	Phone:	_____
Fax:	_____	Fax:	_____
Email:	_____	Email:	_____
Reference#:	_____	Reference#:	_____

Care Manager

Contact Name:	_____
Company:	_____
Address:	_____
City/St/Zip:	_____
Phone:	_____
Fax:	_____
Email:	_____

Patient Advocate

Contact Name:	_____
Company:	_____
Address:	_____
City/St/Zip:	_____
Phone:	_____
Fax:	_____
Email:	_____



LOGS

Logs, logs and more logs

This section provides structure to the patient or caregiver to assist in keeping track of temperatures, reactions to treatments, diet, nausea, mouth sores and more. The purpose is to keep accurate detail of your experience in order to facilitate sharing with your doctor. The more s/he knows, the better s/he can determine the right course of treatment for you.

The following logs are included:

- Diet Log
- Wong – Baker FACES Pain Rating Scale
- Symptoms Log



Diet Log

Good nutrition is important. This is especially true for persons with serious illnesses such as cancer. As is always the case, any changes to one's diet should be made in consult with a qualified doctor.

This log was created as a means by which to assist the interested cancer patient in keeping better track of what is consumed. A well balanced diet is ideal, however keep in mind that during the course of your treatment, any food may be better than none at all. Make sure to talk with your doctor about your diet. S/he can suggest nutrition goals based on your individual set of circumstances.

DATE	FOOD	DRINK



DATE	FOOD	DRINK



Wong-Baker FACES Pain Rating Scale

The Wong-Baker FACES Pain Rating Scale¹ was created by Dr. Donna Wong in order to better assess pain in children. Since its creation the FACES Scale has been widely used by doctors and nurses in assessing the pain of both children and adults in a variety of settings.

The FACES scale is included in your *Sarcoma Survivor Starter Notebook* in an effort to assist you in better assessing and documenting your own pain throughout your treatment course. Today, doctors and nurses recognize the importance of controlling pain to the greatest possible extent. As such, it is important to let your doctor and/or nurse know about your own experiences so that s/he can assist you in developing the best treatment plan.

Instructions: Each face is for a person who feels happy because he has no pain (hurt) or sad because he has some or a lot of pain. Face 0 is very happy because he doesn't hurt at all. Face 1 hurts just a little bit. Face 2 hurts a little more. Face 3 hurts even more. Face 4 hurts a whole lot. Face 5 hurts as much as you can imagine, although you do not have to be crying to feel this bad.

Choose the face that best describes how you are feeling each day. Make sure to note your experience (on the log included in your notebook if you prefer). This will be important information to share with your care provider at your next visit.



¹ The FACES Pain Rating Scale was developed and copyrighted by Wong D.L., Hockenberry-Eaton M., Wilson D., Winkelstein M.L., Schwartz P.: *Wong's Essentials of Pediatric Nursing*, ed. 6, St. Louis, 2001, p. 1301. Its use for anything other than for, by or with patients is not allowed without express written consent of the original authors.



SYMPTOM LOG

DATE	TEMP	NAUSEA Indicate: None Mild (some upset stomach) Moderate (vomited some) Severe (unable to keep food/drink down)	MOUTH SORES Indicate: None Mild (some soreness) Moderate (interfered with eating) Severe (unable to eat b/c mouth)	PAIN See FACES Pain Scale	OTHER Any other symptoms should be noted here to be shared with your doctor or nurse



SYMPTOM LOG

DATE	TEMP	NAUSEA Indicate: None Mild (some upset stomach) Moderate (vomited some) Severe (unable to keep food/drink down)	MOUTH SORES Indicate: None Mild (some soreness) Moderate (interfered with eating) Severe (unable to eat b/c mouth)	PAIN See FACES Pain Scale	OTHER Any other symptoms should be noted here to be shared with your doctor or nurse



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MEDICAL RECORDS

It is important for each of your care providers to have a complete copy of your medical record. In fact, if you are at the center of your care team, then it likely makes sense for you to have one too. Throughout the course of your treatment you (or your support person) and your doctors may refer back to parts of your medical record. As such, it is recommended that you always ask for copies of lab values, results, tests and other impressions as they are added to your record. The average cancer patient can accumulate a pretty thick medical record in a very short period of time. Because of this, building your own “shadow” record as your official hospital or clinic record grows makes a great deal of sense.

Get in the habit of asking for copies of additions to your medical record before you leave each appointment. Then keep the most recent information in this section for easy reference when you or maybe another specialist needs it in the future.



RESOURCES

The speed at which information is exchanged on the Internet makes it impossible for us to guarantee that the sites listed below are operational. If you discover that a link or site is no longer accurate please let us know. Additionally, if you find a site that is particularly helpful we would love to list it for others.

Please send all information change/update requests to info@sarcomacancer.org.

Online Resources:

What is Sarcoma? General Information & Resources

Amschwand Sarcoma Cancer Foundation

www.sarcomacancer.org/index.php?page=research

ASCO Sarcoma Cancer Portal - Articles and Abstracts

sarcomaca.asco.org/

Association of Cancer Online Resources -- Cancer List

www.acor.org/types.html

Beatsarcoma.org - Links to articles for newly diagnosed sarcoma patients

stories.beatsarcoma.org/2011/10/must-read-articles.html

Dana-Farber Cancer Institute - Dr. George Demitri

www.dana-farber.org/Health-Library/What-is-sarcoma-and-how-is-it-treated-.aspx

Dr. Stephen Fadem's Sarcoma Page

www.nephron.com/sarcoma.html

Liddy Shriver Sarcoma Initiative

www.sarcomahelp.org/

National Cancer Institute - A Snapshot of Sarcoma (information about federal funding for sarcoma research)

www.cancer.gov/aboutnci/servingpeople/snapshots/sarcoma.pdf

Sarcoma Alliance

www.sarcomaalliance.org/

Sarcoma Alliance for Research through Collaboration (SARC) Information on Sarcoma Clinical Trials

www.sarctrials.org

Texas Children's Cancer Center

www.txccc.org/



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Washington Cancer Institute
www.sarcoma.org/

Angiogenesis

Angiogenesis Information
money.cnn.com/magazines/fortune/fortune_archive/2000/05/29/280604/index.htm

The Angiogenesis Foundation
www.angio.org/

Biographies/Survivorship Issues

CancerForward: The Foundation for Cancer Survivors
www.cancerforward.org/

Sarcoma Alliance
www.sarcomaalliance.org/Stories/stories.html

Beat Sarcoma
www.beatsarcoma.org/index.php

Cancer Advocacy

American Cancer Society Cancer Action Network Inc.
www.acscan.org

National Coalition for Cancer Survivorship
www.canceradvocacy.org/

Patient Advocate Foundation
www.patientadvocate.org

Stand Up To Cancer
www.standup2cancer.org/

Cancer Clinical Trial Information

CenterWatch Clinical Trials Listing Service
www.centerwatch.com/

Coalition of National Cancer Cooperative Groups
www.cancertrials-help.org

EDICT - Eliminating Disparities in Clinical Trials, Baylor College of Medicine
www.bcm.edu/EDICT

National Cancer Institute Clinical Trial Information
www.cancer.gov/CLINICALTRIALS



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Sarcoma Alliance for Research through Collaboration (SARC) -- Information on Sarcoma Clinical Trials

www.sarctrials.org

Chemotherapy

The Chemotherapy Foundation

www.chemotherapyfoundation.org

Complementary/Alternative Medicine

MD Anderson Complementary/Integrative Medicine Education Resources (CIMER)

www.mdanderson.org/departments/CIMER/

National Center for Complimentary and Alternative Medicine (NCCAM)

www.nccam.nih.gov/

National Institutes of Health: Office of Cancer Complementary and Alternative Medicine

www.cancer.gov/cam

The Cancer Project

www.cancerproject.org

Drug Info

Rx List - The Internet Drug Index

www.rxlist.com/

Rx.com

www.rx.com/

Drug Research Updates

FDA Cancer Liaison Program

www.fda.gov/ForConsumers/ByAudience/ForPatientAdvocates/CancerLiaisonProgram/default.htm

Marti Nelson Cancer Foundation

www.canceractionnow.org

Ewings Sarcoma

Cure Our Children

www.cureourchildren.org

Financial Assistance: Basic Living Expenses

Children's Cancer Recovery Foundation (800) 238-6479

www.childrenscancerrecovery.org

Life Beyond Cancer Foundation (800) 282-LBCF

www.lifebeyondcancer.org



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Financial Assistance: Government Assistance

Medicaid (877) 267-2323

www.cms.gov/medicaid/consumer.asp

Social Security Administration - Disability Benefits (800) 772-1213

www.ssa.gov

State Children's Health Insurance Program (877) KIDSNOW

www.insurekidsnow.gov

Financial Assistance: Prescription Expenses

American Cancer Society (Local Chapters) (800) ACS-2345

www.cancer.org

Cancer Care (800) 813-HOPE

www.cancercare.org

Partnership for Prescription Assistance (888) 4PPANOW

www.pparx.org

RxAssist

www.rxassist.org

Financial Assistance: Transportation and Travel Resources

Air Care Alliance (888) 260-9707

www.aircareall.org

Air Charity Network (877) 621-7177

www.aircharitynetwork.org

Corporate Angel Network (866) 328-1313

www.corpangelnetwork.org

Needy Meds - Links to Assistance Programs

www.needymeds.org

Sarcoma Alliance (415) 381-7236

www.sarcomaalliance.org

General Cancer Information & Resource Sites

Association of Cancer Online Resources, Inc. (ACOR)

www.acor.org

American Cancer Society

www.cancer.org/



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American Society of Clinical Oncology

www.asco.org/

Cancer and Careers

www.cancerandcareers.org

Cancer Index

www.cancerindex.org

Cancer Information & Support Networks

www.texasccancer.info/

CancerNet: PDQ - NCI's Comprehensive Cancer Database

www.cancer.gov/cancertopics/pdq/cancerdatabase

Cancer Source - Information for Patients, Doctors, & Nurses

www.yourcancersource.com/

Caring Bridge - A Nonprofit Connecting Family and Friends When Health Matters Most

www.caringbridge.org

Kids Need Information Too (KNIT) - Information for children whose loved ones are affected by cancer

<http://www.mdanderson.org/patient-and-cancer-information/guide-to-md-anderson/patient-and-family-support/child-life-journal.pdf>

Medscape Oncology Home Page

www.medscape.com/hematology-oncology

National Cancer Institute

www.cancer.gov/

National Comprehensive Cancer Network

www.nccn.org/

Oncolink - Cancer Info for Professionals and Lay Persons

www.oncolink.upenn.edu/

Patient Resource Cancer Guide

www.patientresource.net

Steve Dunn's Cancer Guide

www.cancerguide.org/

Texas Children's Cancer Center

www.texaschildrenshospital.org/carecenters/cancer/



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General Medical Online Research Sources

National Library of Medicine - Access to Medline and Life Science Journal Articles - Free Searches of US National Library of Medicine (NLM Gateway)

www.ncbi.nlm.nih.gov/entrez/query.fcgi

Research - Anything!

www.refdesk.com

US Department of Health and Human Services - Healthfinder

www.healthfinder.gov

Virtual Hospital

www.vh.org/

Housing Assistance - Houston, Texas

Amschwand Sarcoma Cancer Foundation's Corporate Housing Program:

ASCF's Corporate Housing Program lessens both the financial and emotional toll for out of town sarcoma patients seeking treatment, follow-up and care from Houston specialists by offering free housing in the Medical Center.

www.sarcomacancer.org/index.php?page=corporate-apartments

Housing Assistance

American Cancer Society (Hope Lodges) (800) ACS-2345

www.cancer.org

American Childhood Cancer Foundation (800) 366-2223

www.acco.org/

Fisher House (888) 294-8560

www.fisherhouse.org

Hospitality Homes (888) 595-4678

www.hosp.org

National Children's Cancer Society (314) 241-1600

www.nationalchildrenscancersociety.com

Ronald McDonald House Charities (630) 623-7048

www.rmhc.com

Amschwand Sarcoma Cancer Foundation - Adjunctive Treatment

www.sarcomacancer.org/adjunctive-treatment

The Doctors Doctor - Interpret Pathology Reports

www.thedoctorsdoctor.com/



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Online Sarcoma Support Groups

ACOR Mailing Lists - Cancer Support Groups and Info

www.acor.org

Chondrosarcoma Support Group

www.chondrosarcoma-support.org

Endometrial Stromal Sarcoma Support Group

health.groups.yahoo.com/group/Endometrialstromalsarcoma/?v=1&t=search&ch=web&pub=groups&sec=group&slk=3Sarcoma

Epithelioid Sarcoma Support Group

health.groups.yahoo.com/group/Epithelioid_Sarcoma/?v=1&t=search&ch=web&pub=groups&sec=group&slk=15

Ewings Sarcoma Support Group

health.groups.yahoo.com/group/ewingssarcoma/?v=1&t=search&ch=web&pub=groups&sec=group&slk=49

Rare Cancers

Alliance Against Alveolar Soft Part Sarcoma

www.alveolarspsarcoma.net

National Organization for Rare Disorders

www.rarediseases.org

Rare Cancer Alliance

www.rarecancer.org

Research

American Association for Cancer Research

www.aacr.org

American Insitute for Cancer Research

www.aicr.org

Cancer Research Prevention Foundation

www.preventcancer.org

Cancer Research Institute

www.cancerresearch.org

Sarcoma Centers

Dana Farber Cancer Institute

<http://www.dana-farber.org/>

Boston, Massachusetts

(617) 632-3000



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Fox Chase Cancer Center

<http://www.fccc.edu>

Philadelphia, Pennsylvania

(888) 369-2427

H. Lee Moffitt Cancer Center

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

Tampa, Florida

(888) 860-2778

Huntsman Cancer Institute

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

Salt Lake City, Utah

(801) 585-0303

James Cancer Hospital and Solove Research Institute at The Ohio State University

<http://www.jamesline.com/>

Columbus, Ohio

(614) 293-5066

M.D. Anderson Cancer Center

http://www.mdanderson.org/Care_Centers/Sarcoma

Houston, Texas

(713) 792-6161

Memorial Sloan-Kettering Cancer Center

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

New York, New York

(800) 525-2225

Roswell Park Cancer Institute

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

Buffalo, New York

(716) 845-3516

Seattle Cancer CareAlliance

<http://www.seattlecca.org/patientsandfamilies/adultcare/clinicalProgs/sarcoma/>

Seattle, Washington

(206) 288-1024

University of Michigan Comprehensive Cancer Center

<http://www.cancer.med.umich.edu/>

Ann Arbor, Michigan

(800) 865-1125



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Soft Tissue Sarcoma

AMM Eggermont MD, Daniel Den Hoed & Soft Tissue Sarcoma People Org.
www.stsp.org/

U of Pennsylvania OncoLink Sarcoma Page
www.oncolink.org/types/types.cfm?c=17

World Health Organization Histological Classification of Soft Tissue Tumours
www.springer.com/medicine/pathology/book/978-3-540-56794-3

Young Adults

I'm Too Young For This
www.imtooyoungforthis.org

Planet Cancer
www.planetcancer.org

Young Survival Coalition
www.youngsurvival.org



Reading List:

Dietary

- *The Cancer Recovery Eating Plan*; Daniel W. Nixon, MD.
- *What to Eat If You Have Cancer: A Guide to Adding Nutritional Therapy to Your Treatment Plan*; Maureen Keane, MS & Daniella Chace, MS.

Informational

- *Cancer: 50 Essential Things To Do*; Greg Anderson
- *A Cancer Battle Plan: Six Strategies for Beating Cancer From a Recovered "Hopeless Case"*; Anne Frahm
- *The Cancer Breakthrough You've Never Heard Of*; Richard A. Evans M.D.
- *Cancer: Increasing Your Odds for Survival - A Resource Guide for Integrating Mainstream, Alternative, and Complementary Therapies*; David Bognar
- *Finding the Money: A Guide to Paying Your Medical Bills*; Diane Tolley
- *Prepare for Surgery, Heal Faster: A Guide to Mind_Body Techniques*; Peggy Huddleston
- *The Support Group Sourcebook : What They Are, How You Can Find One, and How They Can Help You*; Linda L. Klein

Complimentary Mind/Body

- *Give the Gift of Healing: A Concise Guide to Spiritual Healing*; Rosemary Altea.
- *Health & Healing*; Andrew Weil, M.D.
- *Shaolin: Nei Jin Qi Gong*; Peter Fenton, PhD
- *Spontaneous Healing*; Andrew Weil, M.D.

Personal Stories

- *It's Not About the Bike: My Journey Back to Life*; Lance Armstrong.
- *Autobiography of a Face*; Lucy Grealy
- *At Face Value*; Terry Healey

Spiritual

- *The Seat of the Soul*; Gary Zukav
- *When Bad Things Happen to Good People*; Harold S. Kushner

Inspirational

- *Cancer as Initiation: Surviving the Fire: A Guide for Living with Cancer for Patient, Provider, Family, or Friend*; Barbara Stone
- *Love, Medicine, & Miracles: Lessons Learned About Self-Healing from a Surgeon's Experience with Exceptional Patients*; Bernie Siegel, MD
- *You Gotta Keep Dancin': In the Midst of Life's Hurts, You Can Choose Joy!*; Tim Hansel

For Caregivers

- *Caregiver's Reprieve: A Guide to Emotional Survival When You're Caring for Someone You Love*; Avrene Brandt, PhD



On Death and Dying

- *On Death and Dying: What the Dying have to Teach Doctors, Nurses, Clergy, and Their Own Families*; Elisabeth Kubler-Ross
- *Reaching to Heaven: A Spiritual Journey Through Life and Death*; James Van Praagh
- *The Tunnel and the Light: Essential Insights on Living and Dying*; Elisabeth Kubler-Ross, MD
- *When Dinosaurs Die: A Guide to Understanding Death*; (For Children) Laurie Brown & Marc Brown

Humor

- *Not Now I'm Having a No Hair Day: Humor and Healing for People with Cancer*; Christine Clifford



PERSONAL SUPPORT NETWORK

As a patient or caregiver, friends and family will often ask you what they can do to help. This section organizes your personal support network.

Establish a Network Coordinator. Your network coordinator will be the main person your friends and family will contact to assist you. The network coordinator will also be the person who delivers patient information. The patient must establish boundaries regarding the amount of information they may want to share. People will not know what you want or are comfortable sharing unless you tell them. Recognize that people who care about you may ask for more than you want to share. Your network coordinator can politely but firmly let them know. Set expectations early by letting people know that you may be unable to return phone calls or email during this difficult time. Your network coordinator will also be helpful in this area.

Delegate tasks. Remember you do not have to personally do everything. You or your network coordinator can delegate non-essential tasks to others who want to help in some way. Keep a “honey do” list of things you need done (or may need done in the future). Some examples may be:

- Doing the laundry
- Taking out the trash
- Bringing dinner to the family on certain nights
- Going to the post office
- Picking up the dry cleaning

If someone asks what s/he can do to help, you will have a list prepared to delegate the task. Remember that by delegating a task to a friend or other family member, you are allowing that person to feel good about contributing to your recovery.

The following sheet will help you keep track of the various tasks you may choose to delegate, to whom they have been delegated and when.



To Do List

Task	Date Needed By	Delegated to (include phone number where s/he can be reached)	Comments



DOING YOUR OWN RESEARCH

Studies have shown that it is beneficial for patients to remain involved and proactive in their treatment. One way to be proactive is to learn as much as possible about sarcoma and more specifically to learn about the latest research being conducted concerning your particular sarcoma. The Internet is a wonderful tool in finding this kind of information, but at times it can be confusing and overwhelming. Also, one should be aware that there is a certain amount of inaccurate information on the Internet.

There are several sites that provide search tools that look for quality and reliable medical articles on different cancers. Prior to beginning your search, it is helpful to identify key words and alternatives to use in a search. Keep in mind that neoplasm and malignancy are just other terms for cancer, so perhaps use those words if you do not get search results using cancer or sarcoma. The search engines utilize Boolean logic (AND, OR, NOT) to refine searches. For instance you might input “angiosarcoma AND chemotherapy” to further specify your desired search results. To help you get started, detailed below are four trustworthy sites that provide searches for abstracts and citations about cancer research.

National Library of Medicine

<http://www.ncbi.nlm.nih.gov/entrez/query.fcgi>

PubMed is the National Library of Medicine’s journal literature search system. This site provides access to over 12 million MEDLINE citations and additional life science journal citations. The site also provides links to many other sites, which offer the full text version of the medical articles.

Located on the left side of the web site under the heading “Entrez PubMed” is a listing for the site’s Tutorial. The tutorial provides a very helpful and thorough explanation of how to search for journal literature using this site. The tutorial explains how to limit your search for specific dates or languages and also discusses the site’s preview feature that allows you to refine your search after you see how many entries appear.

National Cancer Institute

www.cancer.gov

The National Cancer Institute’s web site provides a search engine for its bibliographic database named Cancerlit. This database is updated monthly and contains more than 1.8 million citations and abstracts from over 4,000 different sources including biomedical journals, proceedings, books, reports, and doctoral theses. The search page for the database allows you to define your search by subject, publication type and/or year, and language. http://www.cancer.gov/search/cancer_literature

The NCI site offers prepared literature searches for certain topics under its Cancerlit Topic Search heading. http://www.cancer.gov/search/search_cancertopics.aspx

Soft Tissue Sarcoma is one of the topics, which has a prepared search page. Each edition of the prepared search only includes those citations new that month. The last six editions (the last six months) are included on the site.

The NCI’s web page also offers live online assistance with its LiveHelp service. Click on the LiveHelp icon for instructions.



Medscape

<http://www.medscape.com/hematology-oncology>

Medscape provides searches for MEDLINE and also for its primary source online medical journal, Medscape General Medicine. The search box is located at the center top of the page. Click on MEDLINE to view the search page where you can limit your MEDLINE citation search to certain parameters such as dates, language, or specific articles or journals. In order to view the abstracts of the MEDLINE journal citations, you must register at the site. It is free to register.

Your search will create a Search Results page that has a citation for each relevant article. Clicking on the article title will allow you to view the abstract for that particular article. Above most of the abstracts are icons, which can be used to either purchase a hard copy of the complete article text or to view the text in full online.

You can also search Medscape's DrugInfo database that contains comprehensive drug information that is searchable by drug name or disease. Click on DrugInfo tab.

Sarcoma Alliance for Research through Collaboration

<http://www.sarctrials.org>

SARC is comprised of world known experts in the field of sarcoma from each of the major sarcoma centers. The organization is a non-profit dedicated to the development and support of clinical trial research for the prevention, treatment and cure of sarcomas.

Hopefully you will find these sites, and the information that they contain, helpful in your search for relevant sarcoma research and information. Be certain to share and discuss your findings with your doctor and other members of your health care team.



CLINICAL RESEARCH STUDIES

Clinical trials are important in studying all aspects of medicine, not just cancer. All new treatments (drugs and medical devices) must go through clinical trials before being approved by the FDA for general use.

Clinical trials are usually conducted in distinct phases. Each phase is designed to answer specific questions. There are advantages and disadvantages to taking part in each phase of clinical trial. Phase I trials generally assess the safety of the drug or treatment while Phase II trials look at the effectiveness of a treatment. Phase III trials compare the safety and effectiveness of a treatment against the current standard treatment.

Phase I trials are the first studies that use people as participants. The treatment has already been tested in a laboratory setting and on animals, but these studies cannot always predict how a human subject will react to treatment and the side effects that may occur. These studies usually involve a small number of participants and are usually reserved for patients that do not have other good options left.

Phase II trials doctors are assessing how the cancer responds to a treatment. This may include the shrinkage of a tumor or it may be an increase in the time before a cancer returns. Larger numbers of patients are used in Phase II trials than Phase I. Generally, placebos are not used in these trials.

Phase III trials usually include several hundred patients and are often conducted in more than one location at a time. Patients are chosen to receive either the new treatment or the standard treatment. Usually the trials are “double blind” meaning neither the doctor nor the patient knows which treatment the patient is receiving.

Information on clinical trials available can be found several places. There is no one place to get information on all the government and private clinical studies and new studies are continually starting.

The National Cancer Institute (NCI) provides the Physician Data Query (PDQ), which is a comprehensive database of cancer information. It contains a database of both open and closed clinical trials. From the NCI’s home page (www.cancer.gov) click on the UT clinical trials tab located near the top of the page. There are step-by-step instructions on searching the database for clinical trials. Or the general public can call the NCI’s Cancer Information Service (1-800-4-CANCER) to request a customized search of the PDQ database.

The National Institutes of Health (NIH) maintains an even larger database of clinical trials at <http://clinicaltrials.gov/>, but not all of these are cancer-specific.

The Coalition of National Cancer Cooperative Groups (CNCCG) provides a list of cancer studies being conducted at member institutions on their Web site <http://www.cancertrials-help.org/>.

Major cancer centers often offer lists on their Web sites of the clinical trials being conducted there. Private companies, such as pharmaceutical or biotechnology firms, may list the studies they are sponsoring on their Web sites. This can be helpful if you know the company developing a particular drug or treatment. http://www.cancer.org/docroot/ETO/ETO_6.asp

There also are several private firms which match patients with studies for which they may be eligible. These firms usually offer their services to patients free of charge and are paid a referral fee from the organization conducting the study. The **American Cancer Society** (ACS) works with EmergingMed to provide a free, confidential, and reliable matching and referral service to patients looking for clinical trials. For more information, go to the ACS web site. http://www.cancer.org/docroot/ETO/ETO_6.asp



FOR PARENTS

For Patients Who Are Parents Too

As is always the case, being both a patient as well as the parent of a young child or adolescent can make a diagnosis of cancer all the more difficult. Coping with your own fears and unanswered questions can be overwhelming in itself but trying to do this while also helping your child to understand his or her role in your treatment plan can be doubly difficult.

Fortunately, there are a number of resources available to assist the parenting patient in talking with his/her child. The following section has a list of the many resources available as well as places to go for support. Generally speaking, try to be as honest as you can with your child but stay age appropriate in what you share and how you share it. In fact, you may involve your child in helping you to draft questions for your doctor at your next appointment.

Make sure to reinforce to your child that while you are sick and may start to look and feel different, this does not mean that your love for your child will change. As such, encourage your child to be as involved in your care to the extent s/he wants to be and is capable. For younger children, perhaps suggest s/he assist you in documenting your new journey through the use of photographs, handmade pictures or illustrations, videos or journals.

Most of all remember your child loves you. As a result, s/he may experience a variety of emotions as a result of your diagnosis. Keep him/her involved and avail yourself to planning ways s/he can feel supportive of you during this difficult time.



Resources For Parents Who Are Patients

Non-profit Educational and Support Organizations:

KIDSAID (a sister organization to GriefNet) --Purpose is to give kids their own place to deal with their feelings with other kids who have suffered major losses. The premise is that kids can often help kids better than adults can, because they understand a lot of things that adults might not. The site offers children the ability to post questions about variety of different subjects including grief, sadness, worry, feelings and death. Questions are then answered by a psychologist and posted to the website. The site also offers a creative outlet for children, which includes a game section and a poetry section.

www.kidsaid.com

PO Box 3272, Ann Arbor, MI, 48106

KIDSCOPE --Goal is to help children successfully cope with the diagnosis and treatment of a parent with cancer in an age-appropriate manner. The organization recognizes that the impact of a parent's cancer on a three-year-old child is quite different from the likely effect on a thirteen-year-old. Resources offered include bilingual (Spanish and English) videos, comic books and other creative materials designed to educate children about a parent's cancer journey.

www.kidscope.org

2045 Peachtree Road, Suite 150, Atlanta, GA 30309
(404) 892-1437

Kids Connected --Founded under the premise that when a parent gets cancer, the entire family is affected. Children facing the same fears and sharing similar experiences can be helped by others in a similar situation. Resources offered include: quarterly newsletters, support groups, children's camps, online chat rooms, and other events.

www.kidsconnected.org

27071 Cabot Road, Suite 102, Laguna Hills, CA 92653
1-800-899-2866

MD Anderson Cancer Center's KNIT Program (Kids Need Information, Too) - Provides information to young children with a parent who has been diagnosed with cancer (an unfortunate reality for many children of sarcoma patients). The video shows clips of several families and provides helpful hints on what to do and what not to do when talking to your children about your cancer. This resource is highly recommended.

<http://www.mdanderson.org/patient-and-cancer-information/guide-to-md-anderson/patient-and-family-support/child-life-journal.pdf>



Books and Other Written Resources for Children:

Someone Special is Very Sick

by Jim Boulden, Joan Boulden, Joann Farness, and Brenda Brown

Elfo guides the reader through the difficult circumstances that can arise when a family member has a prolonged illness. Issues addressed realistically in this book include the hospital visit, medicines, fatigue and deteriorating physical appearance. Since children often have concerns they do not know how to express, Elfo demonstrates and validates feelings of sadness, fear, worry, loneliness, and love. Readers are encouraged to talk about their own situation, and suggestions are given for ways young children can help. This is an adaptation of the book *When Someone is Very Sick* for younger children.

(Grades K-2)

When Someone in Your Family Has Cancer

by the National Cancer Institute

<http://www.cancer.gov/cancertopics/when-someone-in-your-family>

Written for young people with a parent or other family member who has cancer. Includes sections on the disease, its treatment, and emotional concerns. A very comprehensive resource. While the readability is more appropriate for older children, the information contained in the document may be helpful to the parent trying to talk to the child.

Talking to Children When an Adult Has Cancer

Published by Macmillan Cancer Relief

<http://www.macmillan.org.uk/>

Advice and information for talking to children when an adult has cancer. Sections include whether children should be told, when, how and what they should be told, explaining about treatment, the kinds of questions children might ask, how they might react, and talking about dying.

Other Websites:

Cancerbackup --Talking to Children

This website has a section for parents who have cancer who want to know how to discuss the issue with their children aged from two to sixteen. It outlines the steps you can take to help your children understand what is happening to you and help you through this difficult time in your family life. The information is also appropriate for grandparents who have cancer. The online booklet is divided into three sections: talking to your (grand)child about cancer, coping with the changes and sharing experiences, good and bad. The information (all online) is comprehensive and even provides information on how to talk to your special needs child about cancer.

<http://www.cancerbackup.org.uk/ResourceSupport/Relationshipscommunication/>



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