



OSTEOSARCOMA: FROM OUR FAMILIES TO YOURS

Second Edition

*Support for OsteoFamilies
By OsteoFamilies*

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Osteosarcoma Families Everywhere



OSTEOSARCOMA:

FROM OUR FAMILIES TO YOURS

Second Edition

Osteosarcoma: From Our Families To Yours
Second Edition, February 2020

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*Dedicated to Ian, Maeve and Vince,
Our OsteoWarriors*

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MIB Agents Mission

MIB Agents is a leading pediatric osteosarcoma nonprofit dedicated to Making It Better for our community of patients, caregivers, doctors, and researchers with the goal of less toxic, more effective treatments and a cure for this aggressive bone cancer.

Programs to Support Doctors, Researchers and the Medical Community

- ✓ MIB Agents FACTOR Osteosarcoma Conference
- ✓ OutSmarting Osteosarcoma Research Grant
- ✓ Testing & Research Directory

Programs to Support Kids with Osteosarcoma and their Families

- ✓ Family Funds- To honor your warrior or angel by funding research and programs to Make It Better.
- ✓ MIB Agents FACTOR Osteosarcoma Conference- bringing researchers, clinicians, surgeons together with patient families to Make It Better.
- ✓ Ambassador Agents- Connecting trained OsteoFamilies with OsteoWarriors in treatment
- ✓ Gamer Agents- An AYA video gaming group of OsteoWarriors
- ✓ Writer Agents- Sending letters of encouragement to OsteoWarriors from around the world.
- ✓ Healing Hearts, A Bereavement Program- For OsteoParents
- ✓ Testing & Research Directory- A guide to testing and research options to either help inform a personal treatment plan and/or contribute to OS research.
- ✓ Prayer Agents- Monthly and urgent prayers and intentions for our warriors and angels.
- ✓ Missions- MIB Agents hosts missions for an OsteoWarrior who has been transitioned to hospice care. Together we create a mission designed for the warrior, an item of comfort or entertainment, or an experience of their choosing.
- ✓ Osteosarcoma: From Our Families to Yours- The book you hold in your hands.



Introduction

from Ann Graham, MIB Agents President and Founder

Dear OsteoWarrior Family,

From Our Families to Yours is a collection of experiences and information from families who have endured what you are going through now. This book was borne of a desire of OsteoWarrior Families past and present to share information that we wish we had when we were first diagnosed.

No two osteosarcoma patients are the same, therefore there is no substitute for the expert care of your medical team. This book is not meant to replace the guidance of your oncology team. It is meant to share resources, information and support.

Just as there are no two patients alike, there are no two families alike. It has been many of our experiences that there are patients, parents and caregivers within the same family that have different approaches to how to best be of service to the patient. One may be the researcher and information-gatherer (this is likely you, as you are reading this), and another may find their place at bedside. Know that both are of equal value and importance in the care of the OsteoWarrior.

We are grateful for our Medical Advisory Team of Alanna Church, MD, John Healey, MD and Matteo Trucco, MD for their service in editing and contributing to this document for accuracy and useful content. *Osteosarcoma: From Our Family To Yours* is the result of work by Elizabeth (Liz) Vallejo, James Reilly, and Maureen Smart who navigated osteosarcoma within their own families with fortitude and grace.

Together with osteosarcoma families everywhere, they Make It Better.

As you navigate the road ahead, know that MIB Agents is here to serve you. If we can be helpful to you, please contact us. In the meantime, be assured of our wholehearted hope and prayer for the best possible outcome for your OsteoWarrior.

With Hope,
Ann Graham
President and Founder of MIB Agents
Osteosarcoma Survivor

Preface

Many of our stories start in a similar manner; there is pain. Doctors say it is likely a sports injury or growing pains. We are told to rest or ice it and go to physical therapy. The pain persists and we find ourselves pushing for further tests, for an answer to the pain. Sometimes our concerns are recognized by our doctors; other times we feel dismissed and have to advocate to find answers. Eventually we hear, ‘We see something and have to do more tests to figure it out.’ This is when the fear, real fear, begins to seep in. Then we hear the C word... cancer. Our world flips upside down and will never be the same again. The magnitude of the situation hits us and the shock sets in.

What? How? Why? WHAT will we do?

For the authors and contributors of this book, there is so much information we wish we had known earlier in our osteosarcoma journey. The learning curve of vocabulary, people, treatments and hospitals is enormous and the stakes couldn’t be higher. For most of us, this knowledge was gained by questioning and searching; but often our understanding was found to be incomplete and unfocused because it is picked up in short 10-minute meetings with doctors and teams, random Google searching and social media posts. The stakes are so high as our loved one’s lives are threatened; and we will do anything to protect our children. When families have access to information and knowledge specific to osteosarcoma, they can help secure the best for their child.

The osteosarcoma journey changes us fundamentally; our view of the world and the way we live our lives dramatically alters when cancer hits the youngest in our families. The details of life that we focus on become irrelevant. We find ourselves re-examining; priorities, activities, health insurance, school and parent/work responsibilities while contemplating our futures. Parts of our lives are put on hold while we focus on this diagnosis and its ramifications. Osteosarcoma (OS) is different from many cancers as our children, or ourselves, are physically challenged from the time right before diagnosis through treatment, and likely for the rest of their lives. Whether our warrior undergoes limb sparing surgery, rotationplasty or traditional amputation, our kid and their limbs will function differently. It doesn’t mean they will not be able to do the activities they did before, but it does require time, healing and possibly a different approach to those activities. It can be a frustrating, scary and

difficult time. While no one chooses to join the osteosarcoma community willingly, you will not find a more dedicated, supportive and wonderful group of people to walk this journey with. You are not alone.

Our hope is this book will offer you a few things:

1. A resource for you to gain knowledge and vocabulary about osteosarcoma and the treatment it demands.
2. An introduction and invitation to become an active participant in the osteosarcoma community.
This community is collaborative: a network of patients, families, doctors, treatment providers and researchers all working together. It is only together that we can help all osteosarcoma warriors and their families gain access to the best care for their disease while looking for better and kinder treatments.
3. This book is our attempt to address the 'I wish I had known...' theme that families share. 'Hindsight is 20/20' and while we don't have a crystal ball, we can share our hindsight.

A common statement within our osteosarcoma community is: 'I wish I had known....' Osteosarcoma is so complex and the treatment introduces an overwhelming number of strangers in the form of oncologists, orthopedic surgeons, sarcoma specialists, general surgeons, pain specialists, nurse practitioners, child life specialists, cardiothoracic surgeons, and interventional radiologists into our lives. The learning curve is so steep but it can be made easier if the warrior and family have a guide to help them make sense of this new life as a cancer patient and/or caregiver.

We are here to Make It Better (MIB) for kids with osteosarcoma. You will see that MIB has a number of hashtags that explain how and why we do the work we do. #BelieveInBetter

#TogetherWeCan
#TogetherWeWill
#GoMakeItBetter
#BecauseOfOurKids
 #BecauseOflan
 #BecauseOfVince

#BecauseOfMaeve
#BecauseOfConner
#BecauseOfAnn
#BecauseOfRyan
#BecauseOfVictoria
#BecauseOfYourChildsName

Chapter One: DIAGNOSIS

Included In This Chapter:

- Introduction to Osteosarcoma
- Categorization of Osteosarcoma
- Online Information Can Be Helpful But...
- Medical Terminology
- The Acronyms of Osteosarcoma
- Tests and Imaging
- Lung Nodule(s)
- Size Of Osteosarcoma In Bones
- Best Treatments for OS
- The Tumor Board
- Our Team
- Hospital and Cancer Terms
- Impact of Treatment on Conceiving Children
- Thoughts From Those That Have Been There



Introduction to Osteosarcoma

Osteosarcoma or osteogenic sarcoma (also known as OS or osteo) is an aggressive malignant primary bone cancer. When OS metastasizes (spreads) it is often to the lungs but metastases to other bones may occur. With about 800+ cases a year diagnosed in the United States, OS is the most prevalent bone cancer affecting children and adolescent/young adults.

Osteosarcoma can occur at any age but the most common age for diagnosis is in children and young adults during growth spurt times . It often begins near the ends of leg or arm bones near joints. Osteosarcoma is rarer in other bones like the pelvis, shoulder, and jaw but unusual sites are increasingly seen in older adults. Given its rarity and time of usual diagnosis, it is common to be misdiagnosed as a benign tumor or dismissed as growing pains.

Most osteosarcomas in children are categorized as high-grade which means they are fast growing and aggressive. Intermediate and low-grade osteosarcomas are very rare and are treated differently than high-grade. This book focuses on high-grade osteosarcoma.

According to the American Cancer Society most known risk factors for osteosarcoma are unavoidable. Other than radiation therapy, there are no known lifestyle-related or environmental causes of osteosarcoma. There is no way to protect against this cancer. Known risk factors are:

- **Age:** risk is highest between 10 and 30 especially during growth spurt years, which indicates it may be related to rapid bone growth
- **Height:** usually tall for age which suggests it may be related to rapid bone growth
- **Gender and race/ethnicity:** more common in males and in African Americans and Hispanic/Latino people
- **Paget disease** of the bone: mostly affects people older than 50
- **Hereditary multiple osteochondromas:** benign bone tumors
- **Inherited cancer syndromes:**
 - Hereditary Retinoblastoma: rare eye cancer which has a mutation in the RB1 gene
 - Li-Fraumeni Syndrome: usually caused by abnormal changes in the TP53 gene
 - Bloom syndrome, Werner Syndrome and Diamond-Blackfan Anemia, etc.

Most osteosarcoma cases are thought to be **somatic gene mutations**; these are acquired gene changes that just randomly occur without apparent cause during life. The somatic gene changes are only present in the tumor cells.

The inherited causes of osteosarcoma (hereditary retinoblastoma, Li-Fraumeni Syndrome, etc) are called **germline mutations** and are present in every cell in the body. Later in this book, we will discuss **genetic testing** which tests cells either of the tumor (to determine mutations that occurred to allow tumor growth) or to a person's regular cells which are tested for a germline reason for the osteosarcoma. If you are concerned about an inherited cancer syndrome, you can ask to see a genetic counselor for their opinion and to decide if germline genetic testing would be beneficial.

Categorization of Osteosarcoma

Types of Osteosarcoma:

The pathology reports from a surgical biopsy will often indicate:

- Type of cancer: osteosarcoma

- Grade of osteosarcoma: high, intermediate or low-grade, more info below
- Grade of cells: a number (this is for the pathologist and not really useful for determining treatment)
- Subtype of osteosarcoma: osteoblastic, chondroblastic, fibroblastic, telangiectatic, more info below

Grade of Osteosarcoma and Cells:

The grade of osteosarcoma (high, intermediate or low) will impact the aggressiveness of the tumor and type of treatment necessary. High-grade osteosarcomas are the most common in children and require aggressive treatment.

The grade of a tumor is NOT the stage of cancer (which will be discussed in next section), but is based upon the appearance of the cells when viewed under a microscope by the pathologist.

At this time, the subtype and grade of cells do not impact treatment and therefore are often not discussed further. We include it here because you will likely hear the subtype during diagnosis.

Subtype of Osteosarcoma (does not impact treatment):

Intramedullary (75% of cases) - arising from the middle of the bone

- Osteoblastic
- Chondroblastic
- Telangiectatic
- Mixed cellular type
- Fibroblastic

Juxtacortical/Surface (7-10% of cases) - arising from the surface of the bone

- Parosteal
- Periosteal

Intracortical (less than 1% of cases) - arising from within the cortex of the bone

Secondary osteosarcoma (often due to a prior cancer treatment like radiation)

- Due to previous cancer, treatment, infection
- Pagets disease
- Bone infarct (an injury that causes lack of blood supply)

- Radiation therapy
- Fibrous dysplasia
- Osteomyelitis
- Metallic implants

**NOTE: At this point, this information is interesting (maybe) but if your family member has high-grade osteosarcoma the treatment is the same, so there isn't need to remember or differentiate the type.

Staging: Other types of cancers often stage their diseases using a number of 1-4, as this helps determine treatment and prognosis. Staging for osteosarcoma is different. Osteosarcoma is staged in 2 main groups: localized and metastatic (with a very rare third group discussed in the next paragraph). **Localized** indicates that there is only one tumor in the primary site and no other evidence of disease elsewhere in the body. **Metastatic** indicates that there are two or more areas of disease.

A third and very rare stage of osteosarcoma is multifocal or multicentric osteosarcoma. It is extremely rare presenting with multiple bone locations (and potential lung involvement) without one obvious primary site.



Online Information Can Be Helpful But...

Internet: The internet is a wonderful tool but can also be a difficult place when a cancer diagnosis arrives- so be cautious! We have so much information at our fingertips but sometimes it is inaccurate and often biased. You will find lots of information, but be sure to evaluate the site to verify its credibility because there is misinformation that may make you unnecessarily scared or fearful. Always check with your medical team before taking action or believing something to be true for you or your child.

Social Media: Social media is a powerful resource and tool. Many families use social media to let their larger family and friend groups know of updates regarding how they or their child is doing. You will also find many cancer and osteosarcoma social media groups that you can follow some are listed in the resources section in the appendix. These provide wonderful support and dialogue about the disease but also come with a negative side that may not be initially obvious.

While input from members of these groups is appreciated, they are also trying to understand and digest very complex medical information for themselves. In the back of your mind remember that they are not medical professionals with details about your specific case and therefore their understanding may be incomplete or inaccurate. Their hearts are likely in a good place but understanding this information while under emotional stress is either challenging or impossible. Find a medical team you trust so that you can get your questions and concerns answered by a professional that knows the specifics of your case.

Watching the news can often leave you feeling very negative as news channels tend to focus on the upsetting events and traumatic happenings in the community. Cancer social media groups can be similar as people often post when they get bad news or have a setback. Those with good news often don't want to make others that haven't received good news feel worse. Therefore, cancer social media groups can be biased because they have very little representation of good outcomes and can over-represent bad outcomes. It is natural that when a family has moved past the disease, their first reaction is to get back to "normal life" and commenting or talking about their positive results are often not represented on the internet.

If during your family's battle you consistently read about other patients dire circumstances, it can pull you down further. It can be difficult to read a lot of stories about other patients relapsing or deteriorating health and can have a negative emotional impact. Many families find they need to limit cancer related social media because it can create a more negative perspective than is healthy. Keeping a positive, while realistic, frame of mind is crucial to navigating this difficult journey.

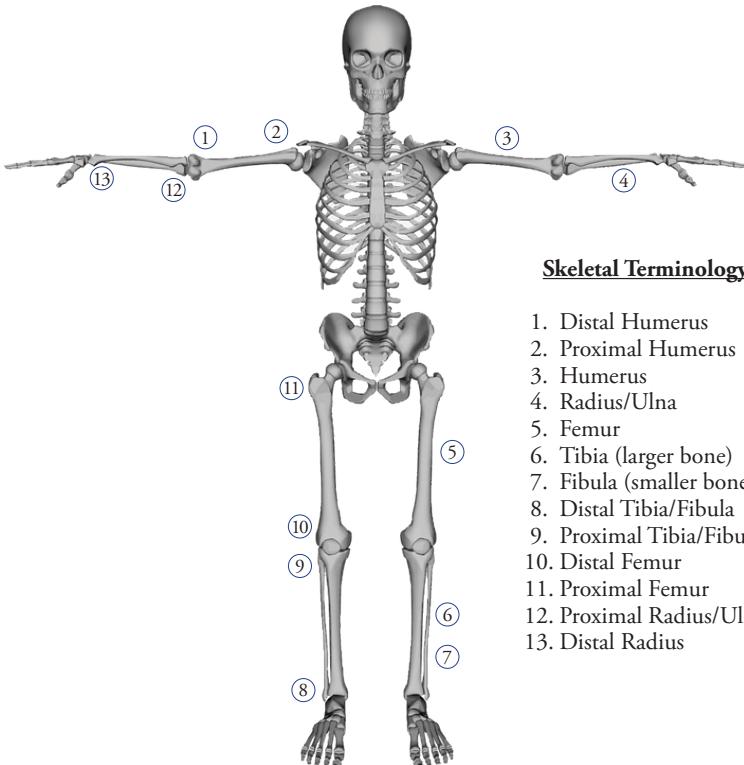
Statistics: Statistics are good when examining an entire population, but not when looking at one case. Your osteosarcoma fighter is unique and their disease is also unique. Statistics are helpful for doctors to determine the course of treatment and options. One doctor wisely said, "Your child doesn't have a 60% or 70% (or any other number) chance of living... They have either 100% or 0%. Your child is unique and we will get him or her the best care so they will have the greatest chance to beat this."

Medical Terminology

As you enter the world of osteosarcoma, the language and terminology can be confusing and overwhelming. You do not need a medical degree but knowing some terminology helps to understand what others are referring to.

During diagnosis, your medical team will talk about the location of the tumor as being proximal or distal. **Proximal** means closer to the torso while **distal** means further away from the torso. The wrist is distal to the elbow and the knee is proximal to the ankle. Since osteosarcoma tumors are often in the long bones, you may hear them say the tumor is in the distal femur, meaning that it is in the long bone of the thigh just above the knee. If it is the proximal femur, that means it is just below the hip in the thigh bone. These same terms may be used for other bones in the leg or arms.

In addition, the terms of “local” and “metastatic” are used to describe the location of the tumor. **Local** is used to describe the primary or original



Skeletal Terminology

1. Distal Humerus
2. Proximal Humerus
3. Humerus
4. Radius/Ulna
5. Femur
6. Tibia (larger bone)
7. Fibula (smaller bone)
8. Distal Tibia/Fibula
9. Proximal Tibia/Fibula
10. Distal Femur
11. Proximal Femur
12. Proximal Radius/Ulna
13. Distal Radius

location of the osteosarcoma. **Metastatic** is used to describe if the osteosarcoma has moved from its local or primary location to a secondary location in the body. While local or primary locations are typically the long bones in the body, osteosarcoma is not limited to them. Metastatic osteosarcoma often targets the lungs, but again that is not the only location.

Cancer control categories are methods of controlling the spread of cancer and killing current cancer cells. **Local control** is used to kill cancer in a specific site of the body. For osteosarcoma, surgery (when possible) is considered to be the best method for local control. Other methods include radiation therapy and cryoablation (freezing). **Systemic control** is used to keep undetected cancer cells from taking root in another location. For osteosarcoma, systemic control usually consists of chemotherapy. Sometimes, immunotherapy (like MEPACT® or mifamurtide) may be utilized.

The phrases **recurrence of osteosarcoma or recurrent osteosarcoma** are used to describe when the disease reappears after the original primary tumor has been treated or removed. A local recurrence is when the osteosarcoma reappears in the same location it was originally found or diagnosed. Metastatic recurrence is when the osteosarcoma reappears in a new location. As aforementioned, one of the more common locations for a metastatic recurrence are the lungs.

Refractory disease is when the tumors are not responding to chemotherapy agents. Often this will require changing chemotherapy to find an agent that slows or kills the tumor cells.

When an osteosarcoma metastasis occurs locally (within the same bone or neighboring joint) it is called a **skip lesion**. While the most common metastases are **systemic metastasis** which occur in other organs, skip lesions are the second most common type of metastasis.

Relapse is interchangeable with recurrent when discussing osteosarcoma. Relapsed osteosarcoma describes the reappearance of osteosarcoma after the primary/original tumor has been removed or treatments completed.

Resection, or surgical removal of an osteosarcoma tumor, is part of most treatment plans for osteosarcoma. The medical team will refer to the tumor as a resectable or unresectable tumor. A **resectable tumor** means

the tumor is in a location where surgeons can remove it with sufficient margin to make the removal successful. Margin is the tissue surrounding the tumor that does not contain osteosarcoma cells but removed to be certain all cancer cells are removed. By doing this there is confidence the entire tumor was removed.

The medical team may refer to a tumor as **unresectable** or non-resectable if the location is such that surgical removal is not possible. It is important to consult with your medical team as treatment for unresectable or nonresectable tumors differs from those that can be surgically resected.

The Acronyms of Osteosarcoma

As with many fields and specialties, cancer and osteosarcoma have a language of its own; and much of it can be in acronyms. It can be overwhelming and confusing for a long time and then suddenly you will find that you are fluent in the language of osteosarcoma. We have included a list of typical acronyms in the appendix so if you are wondering what MAP, LSS, ANC, etc. are, then please look in the appendix.

Tests and Imaging

Biopsy:

Likely you have already had a biopsy since this is the only way to make a definitive diagnosis. There are a few types of biopsies, but a needle core biopsy is one that many children have with an unknown lesion or tumor. A **biopsy** involves either a small incision and a piece of the tumor being removed (open biopsy) or a needle is inserted and a core is taken of the suspicious tumor. This is sent to a **pathologist** who looks at tissue and cells under the microscope to identify what the lesion is. The pathologist may use special stains and genetic tests to make the diagnosis. There are many possible diagnoses for a bone lesion, including benign lesions. The diagnostic process can take up to a week, or longer depending on the experience and specialty of the pathologist at the biopsy facility or hospital.

Bone Scan:

A **bone scan** is used to determine if there are other bones in the body with disease. This test involves an injection of a substance (nuclear tracer) into the vein that is taken up by bone that is actively growing. This nuclear tracer is detected by the medical equipment and creates an image of the patient's skeletal structure that helps your doctor

evaluate changes in bone metabolism. Bone metabolism is increased in areas of growth and in tumor(s), so rather than xray-ing all the bones of the body, this is a one-time full body bone evaluation.

CT (CAT) Scan of the Chest:

- Typically ordered ‘**CT without contrast**’ - which will evaluate if there are any nodules in the lungs. This scan is performed to view thin slices every 2-3mm – most protocols consider nodules 1cm or larger to be concerning for metastatic lesions, but sometimes multiple smaller nodules are also considered concerning. Few very small (2-3mm) nodules can be a normal finding in some people.
- Sometimes ordered ‘**with contrast**’ - which will help with evaluation of lymph nodes or other structures in the chest. This is not routine evaluation as lymph nodes are not usually enlarged with osteosarcoma, but this may help with adjunct evaluation for concerns of infection or something else.

MRI With and Without Contrast:

An MRI can be ordered with or without contrast and evaluates the primary tumor size and extension into the soft tissue/muscles/bone marrow (in the center of the bone). This test will show where the blood vessels and nerves are in relation to the tumor which will help with surgery planning. Contrast is a substance injected into the vein that is used to be able to view certain types of tissues better and give information about the tumor based on how the contrast enters and exits the tumor.

PET Scan (PET/CT):

The PET scan is typically not a standard scan for osteosarcoma, but your doctor may use it in conjunction with, or instead of a bone scan. This scan uses a sugar particle tagged with a tracer to evaluate tissue metabolism. Again, cancers often have increased metabolism so they tend to pick up a lot of the sugar. Several normal tissues take up a lot of sugar, and a tumor or nodule needs to be at least 1 cm to reliably show increased metabolism on a PET scan.

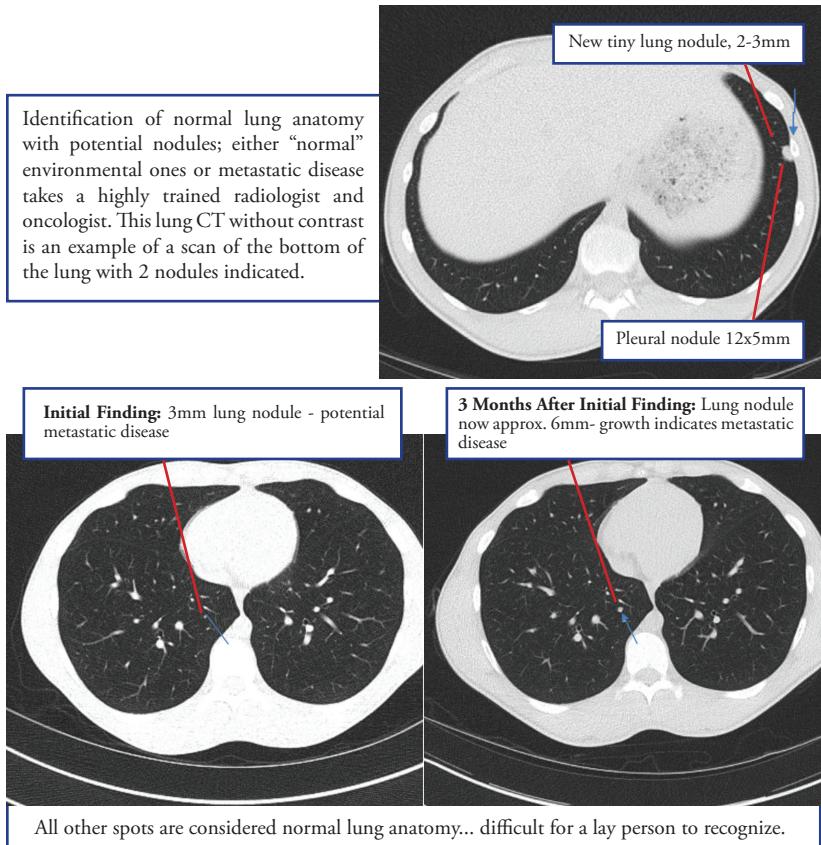
X-Ray:

This imaging allows the doctor to visualize the bone and tumor. The doctor can measure and determine the amount of destruction of the bone and if there are concerns for stability or fracture.

Lung Nodule(s)

"The doctor said the mass seen on the scan may be environmental... what does that mean? How can they tell?"

While the majority of patients do not experience metastases with their osteosarcoma, when metastases do occur, they are usually in the lungs appearing in the form of calcified nodules or masses. Unlike bone tumors, they generally are painless when they are small in size, so they may first be found in an x-ray or CT. Typically, a CT scan will be used to determine if the nodule is osteosarcoma. Nodules, masses or "spots" in the lungs can be due to several things including remnants of a cold or lung infection. However, osteosarcoma nodules are typically spherical growths which can be used to distinguish them from other growths that appear more elongated or flat. If the nodules are too small or unable to determine if they are OS, your oncologist will likely recommend monitoring and



recheck using a CT scan in 1-3 months.

Lung nodules can vary in size. Typically, a nodule ≥ 1 cm is considered a metastasis until proven otherwise. A nodule less than 1cm is generally considered suspicious but unknown if a metastasis. The number of nodules can also vary. Of course, the fewer and smaller the nodules the better, but regardless of size and number the treatment is similar.

A sample of CT scans showing lung nodules is on previous page. Determining what is normal lung anatomy versus concerning spots takes significant training. Lung CT scans were knowingly donated to this project by the patient and his family.

When a nodule is suspected to be osteosarcoma, the standard treatment is to remove the nodule, obtain a pathology report and treat with chemo.

Pleural nodules are nodules or masses in the pleural space of the lung. Pleural space is the thin fluid-filled space around the lungs.

Surgery is often suggested to remove the nodule. There are two common surgeries to remove a nodule. The most common form of lung surgery is a **thoracotomy** which is open chest surgery and allows the surgeon to literally use his/her fingers to ‘feel around’ the lung and remove any other undetected nodules (they feel like pebbles). An alternative surgery is a **thoracoscopy**, where the nodules are removed via small holes in the chest wall with the help of a camera, also known as Video-Assisted Thoracoscopic Surgery (VATS). While the thoracotomy is a more invasive surgery it is often suggested by doctors over the VATS as it often finds smaller nodules to remove that are not seen on scans and may be deeper within the lungs. More information on lung surgeries can be found in Chapter 2 in the surgery section.

If the pathologist confirms the area of concern is osteosarcoma, your oncologist will discuss follow up options to further remove any remaining remnants of OS in the body. Depending on past amounts and types of chemo given, your oncologist may make different recommendations on additional chemotherapy.

In some patients, lung nodules may appear more than once. The treatment can be the same for repeat occurrences or additional therapies may be

added. The concern is the amount of lung functionality remaining after multiple thoracotomies; however, the human body is amazing how little lung function may be required to be viable. The risks and benefits will be weighed by your medical team, and should be an area of questions and discussions you have with your team while evaluating treatment options.



Size Of Osteosarcoma In Bones

Although osteosarcoma tumors are made of a bony network, or grid, that is similar to the composition of regular bone OS does not have the same strength as bone. Therefore, the bone often needs to be supported to prevent breaking and to decrease pain. If the tumor is in the leg this may be done with a cast or boot. Often the use of crutches, a walker or wheelchair are suggested to prevent pain and bone damage. Due to the structure, osteosarcoma tumors do not usually shrink like many other types of cancer. Lung metastasis and soft tissue components of the tumor can potentially shrink but the bony portion of the tumor will rarely decrease in size. Therefore do not be discouraged if the tumor doesn't shrink with chemotherapy because stability in size can often be an indicator that the chemotherapy may be effective. Another indicator that is sometimes used is the percent necrosis of the removed tumor. Percent necrosis is the percent of dead cells in the tumor. Recently, less importance is placed on the percent necrosis as it seems that higher necrosis doesn't always correlate with decreased relapse rates. Necrosis percentage seems to be only one of the factors involved in determining prognosis; people with 100% necrosis have relapsed and those with 5% necrosis have remained cancer-free for a lifetime. Unfortunately, researchers haven't found what other factors indicate the effectiveness of chemotherapy. Scientists need to continue learning about the genetics of osteosarcoma cells to further understand who will relapse and who will not.



Picture from Aufderheide AC, Ragsdale B, Buikstra J, Ekberg F, Vihm TN. Structure of the radiological "sunburst" pattern as revealed in an ancient osteosarcoma. Journal of Paleopathology 1997;9:101-6

The picture to the right is of a femur osteosarcoma tumor in a native Peruvian from approximately 870 years ago. The needle-like projections are calcium deposits of malignant osteosarcoma cells. These

cells have the structure of bone without the corresponding strength. The source of pain with OS is evident in this picture as the needle-like projections are protruding into muscle and ligaments.

Best Treatments for OS

One size does not fit all in terms of your primary doctor, treatment facility or treatment protocol. A high-volume center (HVC) for sarcoma is one that sees many sarcoma patients and has expertise in diagnosing and treating these cancers. It is strongly recommended that sarcoma patients be treated at a HVC for sarcoma, sometimes called a Sarcoma Center. A medical paper entitled “Should Soft Tissue Sarcomas Be Treated at High-Volume Centers? An Analysis of 4205 Patients” by researchers at the University of Miami Sylvester Comprehensive Cancer Center found significantly higher success rates for patients treated at major sarcoma centers. While this advice is great information to consider, you will find patients at HVC that are very pleased with their care and others that are not. High-volume and low-volume centers (LVC) each have their pros and cons; you must choose where you feel you or your child will get the best treatment. If an LVC has all the needed technology and tools along with allowing more personalized care close to home, then it may be the right choice for care. It is even better if they have good working relationships with doctors at HVCs for advising along the journey. The medical center and doctor you choose should be the right fit for your situation and that can always be revised if a better fit is found along the journey. It is common and recommended for patients to seek second opinions along their cancer journey. If treatment needs to continue or potentially be modified due to recurrent or refractory disease, changing doctors or treatment facilities is common as challenging cases require more specialized teams.

Your medical team will discuss their thoughts and recommendations for treatment. Ask questions, and more questions. Keep a notebook with your questions and the answers that you can refer to. There is a science, but also an art, to treating osteosarcoma; modification to standard treatment will be made due to location of tumor(s), size of tumor(s), age and health of patient, etc. You need to find a team you believe is the right fit for your family and the patient; one you can understand and trust in their treatment recommendations. Your loved one should receive the best care for their situation. To determine the best place for treatment, you need to consider: proximity of treatment center to home, trust in the medical

team, ease of transportation, and facilities offered at the treatment center.

Treatment Center and Doctor Suggestions:

1. You should be comfortable with your team. You absolutely should consider second opinions or ask another team's ideas. Your team should be open to you seeking a second opinion. Most teams will give opinions of doctors and facilities with expertise in cases like yours.
2. Sarcoma centers often work with other institutions to provide the best care for patients at other facilities, so you can pursue care at a local facility while getting input from a sarcoma center.
3. Always make sure you are confident in your team and the care they are providing. Since cancer treatment is so challenging, it is normal for your confidence to ebb and weigh, so be sure to continue to ask questions and get your concerns heard. Open communication will help bridge any gaps or misunderstandings.
4. There is no time-frame for choosing another team. You can change teams at any time. Never feel stuck, you must advocate and get the best care you can.

The Tumor Board

A **tumor board** is a meeting where all subspecialty members of the team discuss diagnosis and treatment for specific patients. Not all hospitals have a tumor board, but it is common in many large facilities. The team typically includes the oncologists, surgeons, pathologists, radiologists and case management. They meet regularly to discuss new or ongoing diagnosis and treatment options. This team will also review existing cases at different points throughout treatment to evaluate response and consider changes to the current protocol (regimen). In some cases, nurses, counselors, and/or social workers are included to understand and help discuss how to implement and communicate treatment details to the patient and patient family.

Our Team

Unlike a common cold or flu where you work with your family doctor for all aspects of treatment, a diagnosis of osteosarcoma comes with setting up an entire team to provide the care and treatment needed. Below is a sample list of the types of individuals that may make up your treatment team. Each plays a different and important role in making sure the patient has the necessary care.

Our Medical Team:

Each hospital varies widely on roles and titles but it is helpful to understand common roles and determine how your hospital and team is organized.

Case Manager and/or Nurse Practitioner:

For a diagnosis like osteosarcoma, some hospitals provide a case manager. Most case managers were previously nurses on the floor or clinic. Some hospitals have a nurse practitioner that fills this role. What your treatment center calls them may be different but this person will be one of the people you see most often and help you navigate the multidisciplinary teams and schedules, as this can be challenging. A case manager's or nurse practitioner's role is to coordinate schedules, paperwork, and appointments for all the patient's treatments. They can help provide educational information on tests, treatments and, options. They also coordinate schedules across departments for scans to determine the progress of treatments during and after your primary treatment. You will direct your questions and concerns to your case manager as they coordinate your care with the entire team.

Chaplain/Rabbi/Religious Representative:

The **chaplain** is a religious counselor in the hospital. Most hospitals have chaplains for different religions. They are another resource for families of faith to talk to and seek support. If you would like to request a visit, ask your nurse or child life specialist.

Charge Nurse:

The **charge nurse** is an experienced nurse who is the floor manager. For patients and families, they are a good resource to help if there are any problems with your assigned nurse during your inpatient stay.

Child Life Specialist:

This person is a very helpful resource for pediatric and adolescent patients. **Child Life Specialists** are trained in how to discuss medical topics with young patients. They can show patients what their medical procedures will be like ahead of time such as: what a port-a-catheter is, how it is used and what will happen before, during and after surgery. They can help distract patients during procedures when they are feeling overwhelmed or scared. Child life specialists can also help siblings understand what is happening to their brother/sister

and make them a part of the support team. Most large hospitals have a child life team backed with resources to offer programs both in the clinic and during hospital stays. For example, they offer Arts for Life, Pet Therapy, music programs, and fun events for emotional support. Returning to school after beginning treatment can be challenging as your child will likely be bald, have scars or changed limbs, and have less energy. Sometimes the child life team will help this transition by making a visit to the school to explain to your warrior's classmates what to expect and ways to support their returning classmate.

Family Doctor:

The **family doctor** or pediatrician was most likely involved in tests and diagnostics while chasing the cause of symptoms associated with osteosarcoma. Once osteosarcoma is diagnosed, the family doctor typically takes a back seat to the oncologist. However, during osteosarcoma treatments, it is important to keep the family doctor informed of all treatments and procedures. If your family doctor is associated with the hospital then they will likely be able to see the chart directly. It is good to be certain this will take place as you will eventually return to your family doctor for care after treatment is complete.

Fertility Specialist:

A **fertility specialist** is a doctor that specializes in determining if fertility preservation would be appropriate based upon the gender, age, and timing of treatment.

General Surgeon:

A **general surgeon** is called in for more common surgical needs. This may include the procedure to implant a port-a-catheter. If a recurrence occurs, a general surgeon or thoracic surgeon more familiar with internal surgeries may be called in for the thoracotomy.

Hospital Teacher:

Many children's hospitals have a teacher on staff to help those patients who are missing a lot of school due to treatments. The **hospital teacher** can coordinate homework, projects, and tests with a patient's regular teachers. They help patients complete their schoolwork and minimize getting behind due to hospital stays. Often times they have a special room set up with computers and resource books to assist in

homework. The hospital teacher may work with the school district in conjunction with the social worker or instead of the social worker.

Insurance Case Manager:

Some insurance providers offer their own **insurance case managers** to help clients understand their coverage, treatments and equipment that may or may not be covered. They are typically a nurse by training, similar to the case managers at the hospital. In one example, it was the insurance case manager that educated a family about second opinions and confirmed their insurance offered coverage for a portion of travel in addition to the medical costs. If your insurance company does not call introducing you to your case manager, you can contact your insurance provider to determine if one is available.

Interpreter:

Hospitals offer an **interpreter** that can be either in-person or via phone to help translate difficult medical information in the native language of your family. It is important to ask for an interpreter if English is not your first language. Please do not rely on children to interpret for you - interpreters allow adult conversations to remain among adults.

Nurse:

During your child's stay in the hospital, a **nurse** is assigned to monitor and oversee treatments for them, as well as a small group of additional patients. Your nurse will be the person you see and interact with most on the medical team. Nurses will check in regularly to monitor patients' vitals. They will give any medications ordered by the doctors. If chemotherapy is part of the treatment, they are the one who administers it. A partner nurse will be there to confirm that the patient and prescription match as ordered by your oncologist. In some hospitals, nurses are paired with patients so that you will have the same nurse every time you are admitted. This is nice for the patient and nurse to get to know each other. It allows them to know personalities as well as treatment preferences.

Nurse Assistant:

Many hospitals have **nurse assistants** that aid the nurses in completing their tasks. They are very helpful in collecting vitals and assisting patients.

Nutritionist:

Treatment can interfere with a child's ability or interest in eating. A good **nutritionist** can offer suggestions on food choices and increasing calorie intake to minimize weight loss. They can be a good resource to learn how to make healthy food choices during chemotherapy. Many hospitals have nutritionists on staff, or you can find one to consult with outside of your treatment center.

Oncologist:

The **oncologist** is an expert on cancer and, in some cases, may specialize in sarcomas. All aspects of treatment are run through the oncologist. This is also the doctor you will have the most contact with, probably seeing almost daily while in the hospital.

Orthopedic Oncology Surgeon:

An **orthopedic oncology surgeon** is needed for the initial biopsy and to remove the tumor and any bone it is attached to. They are experts on removing tumors with sufficient margins to reduce the chance of any future recurrence. For osteosarcoma in legs or arms, the surgery can be a limb salvage (or sparing) surgery (LSS), rotationplasty (RP), or an amputation. More details on surgeries are in chapter 2 part B.

Pathologist:

The **pathologist** will examine tissue from biopsies and surgeries under a microscope. Their goal is to determine the appropriate diagnosis and to provide other information that will impact care, such as: if chemotherapy has been successful at killing the tumor and whether the surgical margins are free of cancerous cells.

Non-Medical Personal Team:

Your **personal team** includes your friends, family and the larger community that support you and your child outside of the medical team. While it can be difficult to ask for and accept help, there will be times you will need it. There are many times during treatment that help from your team will be most welcome. Getting used to asking for the help you want and need may be uncomfortable in the beginning but will make your journey significantly better. Being open during this vulnerable time can be difficult. People want to help but most times don't know how to; being specific with requests allow you to have your needs met while also letting your support

system show their love and support. Your loved ones feel powerless in this journey too, and while accepting help may be difficult it will benefit both you and your support team.

Ways to ask for help from your non medical personal team:

- Meals both while in hospital or for your family at home. Eating out can be costly and unhealthy.
- Help with managing drop-off and pick-up for siblings as school and activities.
- Help with laundry, cleaning and lawn care.
- Fun activities and events for siblings.
- School and homework help for warrior or siblings.

From those that have been there: Our personal team can be fluid when going through treatment. Remember, treatment may go on for a while. Many families fighting osteosarcoma are pleasantly surprised when unexpected people help and support throughout this journey, and can be disappointed when others they were ‘sure’ would be around are absent. Focus on allowing your personal team to be there for you—some will be absent but many more will show up when you didn’t expect them to be there. It is important to let those who are there for your family to offer and do what they can. Just like you, family and friends are often struggling to understand what is happening. Allow people to offer support in the way they are able to - it’s therapeutic for them too. It may be inviting the patient’s siblings to do things with their family, it may be meals brought to house or hospital, it may be monetary support, or organizing/participating in blood drives. Don’t feel you have to do it all, let those willing to help do so.

Physical Therapist:

After surgeries, **physical therapists** help the patient regain strength and mobility to minimize any loss of function. As many tumor removal surgeries also remove muscle and bone, the physical therapist is a key part of rehabilitation. Physical therapists will visit patients in their hospital room or home until the patient is strong enough to visit the physical therapy (PT) room/office. PT can be HARD! It can be especially difficult during chemotherapy, but without active participation in PT a patient can risk permanently losing some function of their surgically modified limb.

Psychiatrist:

A **psychiatrist** is a mental health professional who can assist patients or family members with the stress of a cancer diagnosis. They are different from psychologist in that they are able to prescribe medication. Do not be alarmed if your child is put on a ‘psychiatric medicine’. In different dosages, they can decrease nausea and other side effects of treatment. Most kids may benefit from a short course of anti-anxiety or anti-depression medication while coping with cancer and its grueling treatment. Learning coping and acceptance skills can benefit your child and family long term. The psychiatry team joins in the holistic treatment of your child, not just the cancer. If a psychiatrist is not available at your treating institution, then your nurse, social worker or doctor may be able to offer recommendations.

Social Worker:

A **social worker** is a person who is skilled in helping individuals, families, and groups enhance their individual and collective well-being. Your hospital should have one available for you to connect with. When hospital and medical costs become overwhelming, they can link you with local or national foundations that give assistance to families in treatment. They may have access to tangible things that make life easier such as: gas cards, parking discounts, meal vouchers or discounted hotel rates. Social workers can also help suggest support groups or activities for parents, siblings, etc. Social workers can assist with tutors during inpatient stays and partner with your school district to create a plan for school. Social workers can provide your school district the documents needed to develop an Individual Education Plan (IEP) or 504 plan for your child.

Various Hospital Volunteers:

In addition to the formal positions available in most hospitals, many have volunteers that provide additional support, such as:

Play/Activity Rooms: Many hospitals have an activity room for patients. Activity rooms can be general or age specific. Volunteers help staff the activity room. They also visit kids when they are too tired or weak to venture out of their room by bringing toys, games and other diversions to kids in their own rooms.

Therapy Dogs: Every hospital has its own guidelines about therapy

dogs. When allowed, volunteers bring their dogs into the hospital to visit patients in their rooms, hallways or the activity room. Furry friends can be a great distraction, bringing smiles to young ones and parents alike. All therapy dogs complete training and are usually required to be bathed immediately before visiting a hospital.

Local Non-Profit Organizations: Some non-profits visit hospitals on a regular basis. In some cases, they bring books, games or toys for patients to choose from. In other cases, they bring healthy snacks for parents whose children have extended stays at the hospital. Some non-profits even help with household bills or transportation costs related to treatment. The nurses and social workers are good sources of information for what is available in your location. Visit www.MIBagents.org to view a page of resources.



Hospital and Cancer Terms

Hospital Terms:

Most hospitals will differentiate between ‘Clinic’ and ‘Inpatient’ care which each have their own purpose. The **clinic** is where you will be seen for doctor appointments, check-ups, blood draws and out-patient chemo. At clinic appointments, you will see your primary team which includes your nurse practitioner and oncologist. This is where you will discuss treatment plans, potential modifications, and treatment progress. At clinic you may receive out-patient chemo, blood transfusions or medication infusions. These procedures are completed under medical supervision in the clinic and once finished, you will be able to go home. Out-patient chemo is often a full day affair so bringing items of comfort and things to keep you entertained will be important.

Inpatient care requires overnight hospital stays; generally, this is required after surgery, during treatment of infections or fevers, and for most osteosarcoma chemotherapies. Prior to an inpatient stay for chemotherapy, you will have an appointment in the clinic to be sure the warrior’s body is ready for additional treatment.

Osteosarcoma treatment, unlike many childhood cancer treatments, requires you to spend significant time inpatient due to the risk of serious

complications and side effects. Your inpatient team will usually consist of different doctors from your primary team based upon the doctors' rotating schedules. Your inpatient team will be working with you to mitigate side effects from treatment.

Unlike fevers in healthy individuals, fevers are VERY serious for a cancer patient because of their compromised immune system. Your doctors will advise when and where to call if you find your warrior has a temperature. This is crucial information and must be strictly followed. A fever in an immune-compromised patient can be life-threatening and should always receive immediate care as described by your medical team.

Cancer Terms:

A **tumor** is a group of cells that are growing uncontrollably. A tumor can be classified as benign or malignant; a **benign** tumor will not spread to nearby tissue whereas, a **malignant** tumor will spread to near or distant parts of the body. **Cancer** is the result of either malignant tumors or uncontrolled growth within cells of the blood.

There are an overwhelming number of categories and methods when it comes to classifying tumors. Significant confusion can happen upon entering the cancer world. One method of classification is to separate the type of cancer into a **solid tumor** or blood cancer. The US National Institutes of Health (NIH) states that “solid tumors are a mass of tissue and do not contain cysts or liquid areas [whereas] leukemias (and other cancers of the blood) generally do not form solid tumors.” In many hospitals, teams specialize in treatment of different cancers such as: blood cancers, solid tumors or brain tumors. While brain tumors are solid tumors the diagnosis and treatment are different therefore, are sometimes treated by different teams.

NIH also classifies cancer based on the tissue where the tumor originated. There are five types: carcinoma, sarcoma, myelomas, leukemia and lymphoma. As is implied, osteosarcoma is a sarcoma. The NIH defines **sarcoma** as a “cancer that originates in supportive and connective tissues such as bones, tendons, cartilage, muscle, and fat.” Solid tumors are often sarcomas, carcinomas and lymphomas. Blood cancers are myelomas, leukemias and lymphomas. Lymphomas are in both solid and blood cancer categories as they present in both forms.

Cancer treatments are categorized as **local control** (in the specific area of the tumor) and/or **systemic control** (treatment to entire body to kill cancer cells that may have migrated from original tumor).

Impact of Treatment on Conceiving Children

Chemotherapy can impact fertility. Fertility discussions should begin very soon after diagnosis and, if possible, BEFORE any chemotherapy takes place. Depending on your child's disease, age and gender you should determine if any methods for fertility preservation are possible. With the emotional stress of a new diagnosis this can seem like a problem to be considered later. For fertility preservation to be effective, it will need to be considered and addressed prior to any treatment.

Thoughts From Those That Have Been There “I Wish I Knew”

Patient Perspective:

Sloane from Chicago says, “Even though the idea of cancer treatment is really scary, it is usually not as bad as you think it will be. I was told by my mom that I had Osteosarcoma, and later that night I looked it up on the internet. Being a twelve year old looking at all the super-gruesome stories was really terrifying, I was super scared up until the middle of my first chemo. Don’t get me wrong, it was still pretty bad. But it wasn’t nearly as bad as the things we create in our minds.”

Sibling Perspective:

MJ a sister from New York suggests, “I want to encourage new families that this is not the end. Don’t let your fear stop you in your tracks. Don’t stop showing up for your loved one. It’s going to be scary. It’s going to be sad. It’s going to be hellish and there will be times you want to look away -- resist this most natural reaction. The best thing you can do for your loved one is to continue to show up. Show up when you’re scared of what you’ll see, show up when you’re busy, show up when you don’t want to. Company and community is what got my sister through. Cancer is an isolating thing, but we can combat this isolation with courage, compassion and a sense of humor.”

Family Perspective:

Mum from Worcester, England suggests, “Stay positive. Most importantly remember to look after yourself as well.”

Liz from Chicago says, “My son was diagnosed with this cancer I had never heard of; I was absolutely terrified and felt like my mind was whirling 100 mph but I was simultaneously completely paralyzed. A colleague that battled cancer prior visited me and said that the first week or two was the worst, once you have information and a plan of attack it all becomes clearer and you have a way forward. Those words held me over and were accurate for us... once we had a plan we had a way to fight and a way to win.”

Michelle from Virginia suggests, “My first thought when my daughter was diagnosed was “How did I miss this?” She had complained of leg pain for a couple of months and I thought it was growing pains. I felt really guilty for not knowing and for delaying in taking her to the doctor. These thoughts are common but are not productive. You are not at fault in any way. You have a diagnosis now and you will have a great team of doctors, nurses, social workers, nursing care partners, and child life workers who will walk this road with you.”

Yesenia from Progreso, Texas says, “My first initial thought as I hear of someone new diagnosed with this disease is heartbreaking for their families. No one ever should have to go through this, nonetheless a child. One mistake I learned was that I caught myself wanting to keep it a secret from my 8-year-old and had requested child life specialists to break the news to him but then I realized if I wanted my son to trust me during the journey he was about to endure, I had to tell him myself his diagnosis. It is hard but in my personal opinion, I felt the need to tell him myself rather than him finding out through a stranger that we found the reason for his pain and that he has cancer. After this, my son’s trust was towards me all the time for any procedures and we grew this bond like never before. Just be honest and stay strong so they see your confidence despite the storm they are facing.”

Linda from Pennsylvania suggests, “Trust your instincts about your doctors. If you feel a strong connection and a lot of confidence in your doctor, then go with it. If you do not feel confident or feel something is off, go with that as well and look for a doctor you trust and feel confident in. We felt a very strong connection with the surgeon who diagnosed our son and a level of confidence that helped us to have a positive outlook.”

Amanda from New Jersey says, “Pain is temporary and it’s what is necessary to get that disgusting monster out of us. You WILL get through this!”

Lori from Texas suggests, “Do not plan. Take one day at a time... I tried sending out a calendar of my daughter’s chemo schedule. That was revised every day until I gave up. Get duplicates of toiletries and necessities and just keep emergency bags packed. That will also relieve stress during an (inevitable) crisis. Again, connect with those who have gone before. Their help is invaluable!”

Dad from California says, “I found having a person to talk to about challenges as a caregiver was key. I, like most, had good friends and family; but sometimes it was hard to discuss the fears and confusion of being a parent of an osteosarcoma patient with someone so close. I found it helpful to have a support group and in particular at least one other parent to confide in. It is still difficult but sometimes it is easier to unload to someone who isn’t emotionally involved in your own family but understands the difficulties and treatments associated with osteosarcoma. I was fortunate enough to have two dads who shared in the difficulties of being a patient’s father. We could share fears or concerns about treatments or tests. We knew we weren’t shocking each other so we could openly share feelings, fears, and tears in a safe environment.”

B's Mom says, “Act quickly. Keep a positive attitude for your child. There are NO dumb questions, stay informed on your level of understanding. If you don’t understand or know... ASK! Guessing is worse than knowing.”

Mom from Eastern Oregon says, “Ask questions, read articles, join Facebook groups... I found it helpful to learn of other stories and get support from other families. Take it a day at a time, a moment at a time. Take a break when you can to recharge: it can be taking a small walk outside, jog, listen to music, etc. Accept help or ask for help from family/friends for childcare, food, cleaning, etc.”

Jen from Tasmania suggests, “Always question the doctors. If you aren’t satisfied with their answers you have the right to a second opinion. If you think you aren’t being listened to, go higher. Don’t give up until you get a definitive answer which suits the symptoms. Insist on the scans!”

Chapter Two: TREATMENT

PART A: INITIAL CHEMO Neoadjuvant Chemotherapy

Included In This Section:

- The Standard Protocol for OS Treatment
- Impact of Treatment on Conceiving Children
- Tests & Procedures Done Prior to Treatment
- The Purpose Of Chemotherapy Prior To Surgery
- The Purpose Of Surgery
- The Purpose Of Chemotherapy After Surgery
- The First Hospital Admission Expectations
- Life In The Hospital
- Life Outside The Hospital
- Common Hospital Facilities
- The First Chemotherapy
- Discharge from the Hospital
- Safety
- Hair Loss
- Thoughts From Those That Have Been There



The Standard Protocol for OS Treatment

The Children's Oncology Group (COG) protocol for osteosarcoma is MAP chemotherapy. MAP stands for the chemotherapy agents (M) methotrexate, (A) adriamycin (also called doxorubicin) and (P) cisplatin (also called platinol). The MAP regimen consists of 2 cycles which lasts 10 weeks. Surgery recovery is followed by 2 more cycles of MAP (10 weeks) and then 2 cycles of MA (8 weeks). The final 2 cycles do not include "P" as usually the maximum lifetime dose of cisplatin will have been reached. Many doctors do warn that the timeline indicated is if there aren't any delays- which is very rare. Often doctors advise to expect about 20% of treatments for each patient are likely to be delayed by days or sometimes weeks if blood counts are too low or other issues like infection or additional surgery recovery arise.

One cycle of MAP chemotherapy is five weeks long with week one beginning with an infusion of adriamycin, "A" (doxorubicin) and cisplatin, "P" (platinol). There isn't any additional chemotherapy given in week two and three. **Nadir** is when the lowest blood counts are expected

post-chemotherapy. Doctors are looking for when nadir occurs and then for the rebound to be sure the body is ready for additional chemotherapy. These two weeks may seem like a break, but in reality, it is when the fatigue and lethargy often hit the hardest and you or your child will be most susceptible to infection and disease. Then week four and five both begin with methotrexate. Generally, these chemotherapies are all given inpatient with the “AP” usually involving two days inpatient and “M” involving anywhere from 2-6 days depending on how quickly the level of methotrexate decreases in the blood. Round five and six are sometimes only four weeks long as you will not be able to receive more cisplatin. As chemotherapy is put into the body, it must also be expelled or cleared to a level that is safe for the patient to be out of the hospital.

Typical Road Map for COG (Children's Oncology Group) MAP Chemo Protocol

Round 1		Round 2		Round 3		Round 4	
Week	Chemo	Week	Chemo	Week	Chemo	Week	Chemo
1	A, P	1	A, P	Surgery and Recovery		1	A, P
2		2				2	
3		3				3	
4	M	4	M		M	4	M
5	M	5	M		M	5	M

Round 5		Round 6	
Week	Chemo	Week	Chemo
1	A	1	A
2		2	
3		3	
4	M	4	M
5	M	5	M

MAP stands for the chemotherapy agents (M) methotrexate, (A) adriamycin (also called doxorubicin) and (P) cisplatin (also called platinol)

While the above is standard protocol, there are many reasons doctors may decide to deviate from this, including size and number of tumors, the health of the patient, age of the patient, etc. Do not be surprised if this protocol changes. Treatment is not one size fits all and changes occur when the established protocol does not work well for a patient or a specific situation.

While inpatient, doctors and nurses will work to minimize the side effects of chemotherapy and develop a plan for both inpatient and

home care. Side effects will be discussed by your team: nausea, hair loss (alopecia), weight loss, loss of appetite, low blood counts (neutropenia), compromised immune system and mouth sores (known as mucositis, that sometimes go through the entire digestive tract to the other end) are some typical short-term side effects from MAP chemotherapy. Nurses will also keep patients hydrated and deliver chemo-protectant medicines to limit the impact of the chemotherapy on other organs. Dexrazoxane (Zinecard®) is given for heart protection from adriamycin (doxorubicin), leucovorin is given after methotrexate to protect normal cells and mesna is given for bladder protection. Know that it is likely you or your child will experience at least some side-effects. Keep your team well informed, there are many different options to combat side-effects; if one doesn't work, they can try others. Some rare but serious long-term side effects of MAP chemotherapy include heart damage, kidney damage, secondary cancers and hearing loss.

Impact of Treatment on Conceiving Children?

Chemotherapy can impact fertility. Fertility discussions should begin very soon after diagnosis and, if possible, BEFORE any chemotherapy takes place. Depending on your child's disease, age and gender you should determine if any methods for fertility preservation are possible. With the emotional stress of a new diagnosis, this can seem like a problem to be considered later. For fertility preservation to be effective, it will need to be considered and addressed prior to the beginning of any treatment. Balancing the urgent need to begin chemotherapy with the time required to preserve fertility can be challenging; be sure to have these conversations with your medical team.

Tests & Procedures Done Prior To Treatment

Prior to treatment four (sometimes five) things are generally done:

1. Discussion and decisions about fertility preservation
2. Testing for baseline information on organs that can be impacted by chemotherapy
 - a. Echocardiogram and EKG to test the functioning of the heart
 - b. Blood tests to check for marrow, kidney and liver function
 - c. Audiogram to assess hearing
3. Placing a central line (or port) so that: veins are protected from chemotherapy, blood tests are made easier, and administration of IV medications are given without shots. This is done in a short

surgery to implant either a **venous catheter** (usually called a port) or a **Hickman Line** into the large veins in the chest. Discussion of the type of central line that is best for the situation will occur with your medical team.

4. Preparation of medications. Often patients will take pre-chemotherapy medications to help the body tolerate any quick acting side effects. Also, patients will usually be given a prescription for numbing cream that they will use on the site of their central line or port so that the needle insertion is not felt.
5. Sometimes a baseline of a child's neurological functioning is done so that any potential issues with memory or executive functioning can be determined and dealt with if these are impacted from treatment.

The Purpose Of Chemotherapy Prior To Surgery

Chemotherapy prior to surgery is called **Neoadjuvant Therapy**. The goals of neoadjuvant therapy are to:

1. Start killing the osteosarcoma, and any osteosarcoma cells floating around in the blood quickly.
2. Utilize data from the tumor after two rounds of chemo to determine the percent of cells that have died due to the therapy - this is called the "rate of necrosis". Generally, oncologists like to see a necrosis rate of greater than 90%. If less they may consider adding additional chemotherapy agents to treatment. There is currently a considerable debate on the usefulness of necrosis rate to determine survival. Some newer considerations may involve the type of genetic makeup of the osteosarcoma tumor to be a better indicator. While genetic testing has generally not been historically helpful in fighting osteosarcoma; many new trials utilize this information to determine if a patient is eligible for a clinical trial as a trial would target specific genetic mutations in the tumor cells. Therefore, some doctors are encouraging genetic testing, even of initial tumor as this information could be utilized if needed later- see more information in Chapter 4 under genetic testing.
3. Give time to plan surgery. Patients and families need time to consider options available to them. Surgeons need time to prepare for rotationplasty, LSS limb-sparing/salvage or amputation surgery. Customized bone replacements can take approximately two months to manufacture and obtain regulatory approval.

4. Potentially shrink the tumor (if it has a soft tissue component) to be able to get better margins during the surgical procedure.
5. Chemotherapy can many times bring pain relief from the tumor.

The Purpose Of Surgery

Surgery is completed to remove all signs of disease possible from a patient's body. The rule of thumb in osteosarcoma, if a tumor can be removed it should be; as survival rates rise dramatically with complete removal of all detected disease. Occasionally the site of disease will make it unresectable (cannot be removed via surgery due to location) then a different approach and protocol will often be considered.

What Is The Purpose Of Chemotherapy After Surgery?

Chemotherapy after surgery is called adjuvant chemotherapy. This chemotherapy is used to continue killing any osteosarcoma cells that may be left in the body after surgery. These cells could remain due to poor surgical margins (cancerous cells on the edge of the surgical site that still remain). More commonly, there are cancerous cells moving through the blood to other areas of the body. These cancerous cells get into the blood stream via the blood vessels that feed the tumor. These microscopic, malignant cells, called micro-metastases, are present in the majority of patients at the time of diagnosis. The adjuvant chemotherapy is used to kill these cells and prevent any further metastases from taking hold in another bone or the lungs. Since the addition of adjuvant chemotherapy to osteosarcoma treatment, the relapse rates have decreased. So, while chemotherapy is difficult, it is very necessary to keep the osteosarcoma from returning.

The First Hospital Admission Expectations

Because hospital stays may last from 3 to 10 days or more, it is important to bring items that help patients feel comfortable. For convenience, you may want to prepare a suitcase or plastic tub to carry and keep things together between visits, and for that unexpected visit in the middle of the night for a fever. Below is a list of some items you may consider packing. This list will be different based on each individual patient and their likes and interests:

- Photos (family, friends, pets, doing fun things, etc.)
- Special pillow or pillowcase, blanket, or stuffed animal
- Headphones and/or white noise maker
- Coffee maker
- A book that patient is currently reading
- Computer game systems (PlayStation, Xbox, etc.)
- Meaningful things friends have given since diagnosis
 - Crafts
 - Autographed pictures or items from sports or other heroes
- Videos if a DVD player is available in the hospital room
- School work to keep up normalcy
- Overnight stuff for caregiver (at least enough for first night or two)
- Phone, iPod, iPad, laptop, chargers, etc.
- Deck of cards
- Small toys or games
- Favorite snacks/meals for patient and parent or caregiver
- Notebook to journal treatment, medications and how they worked or not, what alternatives did work, doses used, recovery times, and capture questions so you are ready when the doctor visits
- Using a wheeled piece of luggage or a foldable dolly to bring items to and from hospital floor is helpful
- Non-slip socks and/or slippers

For a caregiver staying with the patient, the hospital typically provides a chair/bed, sheets, pillow and blanket. You may want your own pillow or blanket for comfort. Since caregivers may be spending significant time around the hospital to monitor and manage care for a pediatric osteosarcoma patient, they may want to look for items that allow them to be comfortable and perform work remotely if necessary. As challenging as it sounds most of us do have to keep working, at least a little. Do not hesitate or be embarrassed to figure out a way for you to manage care for your child and the ability to work occasionally while at the hospital. Work is not only a needed source of insurance coverage and income but a way to keep you balanced and productive as well as having your child see some ‘normal’ during an abnormal time. If you are trying to work from the hospital, there are portable/collapsible desk options that aren’t too expensive and enable a mini office setup while meeting the needs of your child.

Life In The Hospital

Life in the hospital can be challenging. Your child will likely go through periods where he/she doesn't feel well, is in discomfort from a procedure and usually will learn to associate the hospital with unpleasant times. Putting effort in to counteract this can be work, but is worth the effort. Some suggestions people have tried are:

- Bring room decorations and pictures
- Bring Christmas style lights to hang for ambiance
- Have a new game or art project to work on each admission
- Ask the hospital what entertainment they may have - playroom, magicians, pet therapy, video game consoles, art projects, music therapy
- Arrange visitors when you expect your child to be up for such visits
- Bring your child's pillow, bedding, and heating pad (if allowed)
- Bring regular clothes instead of a typical hospital gown
- Bring a fan or have a soothing noise machine (rain, forest sounds, waves, etc.)
- Favorite toys, video games, art equipment, etc.
- Delicious food and treats

Unfortunately, scheduled hospitalizations are frequent and the unplanned fever hospitalizations happen more than anyone wishes. It can be a good idea to keep a suitcase or plastic storage bins in the car during treatment. Preparing a bag each time will be daunting and possibly delay getting your child to the hospital, this preparation can make a stressful situation less so. Unfortunately it is not unusual for you to go in for a quick blood draw appointment and unexpectedly need to be admitted for an unspecified amount of time. Having a bag/tote packed with necessities you need can make the unexpected more manageable.

When someone asks what they can do for you, tell them! Make a list of things you'd like to keep packed (shampoo, lotion, toothbrush, etc.) so you don't have to buy duplicates of what you use every day. This can be a great way to let people help you in ways that matter. Let this be a win-win – remember people are sincere when they want to help. Sharing what you need or want can be a blessing for both the giver and the receiver.

Most people find keeping some kind of 'normal' in life reassuring. Try to keep some routines in place, maintaining bedtime routines for your

family or remaining involved in as many activities as possible. Your family will need to determine which routines are important and which are not. This may be another great way to accept someone's offer to help. Having rides to and from events can be a great relief for siblings while you are caring for your cancer patient.

Another avenue of 'normal' is school and work. Support and trust your child to find their own way to navigate school. Staying current with schoolwork allows for reentry to school with their friends. For some warriors, staying at the same grade level is very important, while for others it is less important. Having open discussions with your warrior and their education team is crucial. Understanding your warrior's goals for their education (and potential career if they are a young adult) can guide your decisions for education during treatment. You will find warriors that continued school during treatment, ones that did some version of homebound school, others that did online school and some that took a break from school to concentrate on treatment. For some, schoolwork is just too challenging during treatment - learn to make the good days count and don't force more work than can be tolerated on the bad ones.

Build a team to support your patient's academic success; include teachers, homebound instructors, hospital teachers and school administrators on your team. Try not to only support your patient in doing their school work but try to support their educational team by sharing information about treatment so they can understand the demands on your patient. Some people have experience with cancer treatment and may feel that your child's treatment will be similar, usually this is not the case as osteosarcoma treatment is more challenging than most treatment protocols. Helping your support team understand the differences required with osteosarcoma treatment will help them remain dedicated and creative in teaching your child. If your patient's teacher or administrator has no understanding of the treatment for osteosarcoma, they will have no understanding of how hard the patient is working under really difficult circumstances. There are education laws that provide access to education through treatment and supports legally available when your child returns to school.

Life Outside The Hospital

Life outside of the hospital during treatment can look very different from normal. Since so much time is spent in the hospital, routines and relationships shift and change. Most people find that keeping some

regularity and familiarity is helpful and soothing but you will have to determine what is best in your situation. The patient's immune system will be highly compromised at different times throughout treatment, so keeping him/her from contracting illnesses will be incredibly important. You will need to learn to balance the need for normalcy with the need to limit exposure to germs, this can leave you facing a difficult set of decisions. For example, when someone is neutropenic, they may be advised to avoid fresh fruit. What happens if strawberry shortcake is your child's favorite birthday cake and their birthday falls when s/he is neutropenic what do you do? Be creative... if you blanch the strawberries you can use them to make strawberry shortcake - perhaps not as good as including fresh strawberries but a really delicious Plan B! This is a topic to discuss with your doctor and nurses to get rules and guidance on how to best balance the need to be normal and the needing to minimize germ exposure.

Energy, mobility and even motivation can vary greatly not just from patient to patient but may vary greatly in your patient. Making plans can be difficult to impossible no matter how desirable they are. It is important to seize moments and take advantage of every opportunity to make it better. Again, your support team can be invaluable and respond to last-minute invitations and plans in ways they would not be able to normally. People understand. Don't hesitate to invite and include; but remember asking is asking, and not a demand. When you ask, the answer might be a kind, but disappointing, no. While initially there may be a lot of resistance to using crutches or wheelchairs, have these available and encourage using them to make more of these opportunities doable. Some stores have scooter carts that can help your child to get out of the house while not overextending their limited mobility.

Sleep can be challenging at night if you slept all day. If you, or your patient, can't sleep, it may be helpful to stop forcing yourself to sleep. It may be helpful to get out of bed and do something - take a bath, offer a sponge bath, bake a cake, or get out of the house and go to the all-night diner. Sleep may come easier after you stop fighting it, have some fun and go back to bed.

The decision on attending activities and school is an important discussion to have with your medical team. Based upon the patient's age, diagnosis, physical and mental health, the best option for each child is variable and

often changes while treatment progresses. Take one day at a time and make decisions with your team in the best interest of your child. It is also important to talk with your school's principal and see what services are available. Many districts have a home/hospital teaching option but may limit school attendance. It is also important to see how to best educate the teacher(s), and principal and guidance counselor on what is and isn't reasonable to expect. They want to be helpful but may not have a lot of experience knowing how to best support you and your patient. The best resource on school work may be the patient. Don't forget to listen to your patient. Understand their goals and interest in schoolwork and share them with the education team. So much is forced upon your child during treatment, seize every opportunity to enable your child to make choices, and make decisions for him/herself just like they would do before treatment. When school work becomes a choice for your child it may be easier to do.



Common Hospital Facilities

It is important to know what facilities or resources are available at the hospital. The nurses and child life specialists are typically the best resources to let you know what is available and where it is located. Most children's hospitals have an activity room or play area for the kids. Some of the larger hospitals even have multiple rooms available to age-specific groups – like a teen room for older patients. For school-age patients, many hospitals have a school room and an on-site teacher to provide an environment and resources to help them stay current on school work.

Many children's hospitals have a Ronald McDonald House close and an in-hospital Ronald McDonald Family Room. The Ronald McDonald House provides a home-away-from-home for families of children receiving medical treatment at nearby hospitals. Although each house is independently owned and operated, most all offer physical comforts, emotional support, programming for the whole family and referral services. Ask your social worker or someone on your medical team about an RMH close to your hospital. Sometimes in the chaos of diagnosis/admission, this is forgotten; however, this is an invaluable option for families traveling for treatment even if it's just traveling locally but far enough away from home that commuting back and forth to the hospital is difficult or costly.

For longer stays, it is good to know if there is a kitchenette available to patients and their families. Some find it good to have some familiar choices in food that can be kept in the refrigerator or freezer and heated up in a microwave. While hospital food is not near as bad as the stories we hear, it is repetitive, and one more reminder to patients that they are in the hospital. As a result, it is nice to offer options and things that remind them of home. Another option some hospitals have is a food court, where alternate choices are available to mix it up on food options.

On long inpatient stays it is helpful to know where the walk-in shower is for the patient. You can coordinate with a nurse on when to attempt a shower, how to keep areas dry that need to remain dry, how long an IV can be disconnected or how to use pain medicine effectively to get the most out of a shower. Working together is important when your child has limited mobility during recovery from surgery, an illness or side effects from treatment.

Another option at some hospitals is an outside courtyard. It offers a chance to get some fresh air, maybe enjoy some outside play and again gives a chance to get away from the reminders that you are in a hospital. You will likely still have an IV pole and hospital gown or pajamas, but fresh air and green surroundings are a nice change when it is available.

Some hospitals have chapels or meditation rooms, libraries, clothes washing facilities, massage therapists, guided imagery therapist, computer resources, etc. Several families have shared that after 9 months of hospital visits, that “I didn’t know that existed here. I would have used that if I knew.” Always ask the nurses and other parents and you might be surprised at what is available.

The First Chemotherapy

The first chemotherapy treatment is scary for everyone. That is normal. We all have heard stories about how horrible chemo is, but it is a necessary part of the treatment to address osteosarcoma. Before most chemotherapies are administered, there is a regimen of pre-medications or preparation. It may be as simple as liquids to fully hydrate the body or establish a certain level of pH to help flush the chemo from the body safely. Most the time there will be pre-medications to help minimize the side effects like nausea. For some chemotherapies, there will be pre-medications to address some of the more harmful effects chemotherapy

can have on other organs or parts of the body. For example, prior to doxorubicin, a premed of Zinecard maybe given to help protect the heart muscle.

For osteosarcoma, the first treatment is usually a combination of two chemotherapies, doxorubicin, and cisplatin. Both of these are very strong chemos and have their associated side effects. The first thing most patients notice is the color of doxorubicin (nicknamed “the red devil”). It is a reddish orange color. For some patients it is difficult to look at and see that color of liquid flowing through the tube into their body. One trick many have used is a pillowcase over the bag as it hangs on the IV pole or moving the IV pole behind the patient leaving it out of direct sight. Of note, the doxorubicin goes in red/orange and can often stain saliva, tears, and urine with the same red/orange color.

While most anticipate nausea as a side effect of chemotherapy, it doesn't happen immediately for most patients. It may be several hours or overnight before it hits. Even then the severity may vary patient to patient. The doctors and nurses have several medications that can help combat nausea. If one doesn't work they will add or replace with some of the alternatives. Some do cause drowsiness, but that is not a bad thing for some patients as it helps them pass the time of the chemotherapy delivery more rapidly. When awake your child may find activity helps delay the onset of nausea... laughter can be the best medicine. Playing a game, becoming engrossed in a really good movie, using guided imagery to ‘take a trip somewhere else’, or doing homework can delay nausea a little. None of these activities will avoid it. Nausea can be impacted by how well your child is doing overall. How well your child is feeling will impact his/her interest in participating in activities. Trust your child. Encourage your child.

The length of stay for many hospitals will vary based on the particular chemotherapy treatment being given. There are also different policies and procedures based upon the hospital. Some hospitals do nearly all treatments inpatient and others allow patients that are tolerating therapy well to go home each evening with hydration IV's and medications for the evening. Doctors will monitor the side effects and make sure they have these under control before releasing from the hospital. If side effects are not well controlled please contact your doctors to address these concerns. For methotrexate, the treatment or dosage is administered in a single IV

session. However; patients receive a rescue drug, Leucovorin, until the level drops below a threshold set by your team, this can vary from team to team so discuss details with your own team. This is determined by a blood test drawn once a day or more often. For some that is as quick as 2-3 days, but we have heard of cases that took over 10 days to drop below the required level. If it helps you to understand why this important - ask questions. Your treatment team can explain the rationale for long stays while waiting for chemo to clear - remember your child may feel pretty good during this time yet it may not be 'safe' to be discharged. Most patients try to determine what will help lower their methotrexate level the quickest as getting out of the hospital is such a relief. Most come to realize that staying well hydrated, urinating often and staying as active as possible help – there is not any magic trick, it takes time and patience for your body to rid itself of the methotrexate.

Emotional support can be extremely helpful during chemotherapy. Please talk to your team about options for socialization with other patients, art therapy, music therapy, school liaison, psychological support and counseling; many of these supports are offered through your medical facility. Chemotherapy and cancer are so difficult, these can make a huge difference.

Discharge from the Hospital

You will be able to contact the hospital and someone on the oncology team 24/7. When questions or concerns arise - call for advice from the oncology team right away. Your child will be in a medically fragile state while fighting this disease and the chemotherapy takes a toll on their body. What might be just a fever for one child, can be a life-threatening situation for someone in their state. Your doctors will give you thorough instructions concerning symptoms. Err on the side of caution; when in doubt, call. This is not a time to wait and see if they get better.

At home, it will be helpful to have items of support for your child that will make everyday tasks easier. Even if you choose not to use them, you won't know if, and when, you will need it until the moment arises. It is not unusual for your warrior to not want to be confronted with the items mentioned below until they are absolutely needed. They are a tangible reminder of their illness. Many families find that keeping them out of sight, until needed, is a way to protect their warrior's state of mind. Items that may be helpful or necessary at some point:

- Wheelchair
- Crutches or walker
- Bedside urinal
- Bins for emesis (vomit)
- Disposable bags for emesis in the car
- Plastic mattress pad for bed (stress and medications can make wetting the bed normal even for teenagers and unexpected emesis does occur)
- If the bedroom or bathroom is not on the ground floor then determining how to modify the house arrangement temporarily or how your child will move from one floor to the next will need to be considered.
- Determining a method that your child can get your attention anytime in the day or night. Some people have their child sleep near them or use a baby monitor or bell - you will want a way for your child to let you know they need you.

Many people find that when they go out, they need additional items to keep their child comfortable. A small backpack (so that they can wear it while using crutches or walker) that goes wherever your warrior does can be convenient. Some items to take with you whenever going out:

- Medications for pain, nausea, etc.
- Disposable bags for emesis
- Thermometer and alcohol wipes to be sure it is free of contaminants
- Hand sanitizer
- A snack

Neutropenia is when a person's immune system is compromised and they have less white blood cells to help to prevent illness and infection. This is the reason that a fever is extremely concerning as infection can quickly get out of control for a child with a compromised immune system. Having all visitors or people near your child be healthy and use hand sanitizer prior to seeing your child is a typical precaution for many families. Some families have their child or others wear a mask to offer additional protection. Talk to your medical team to determine when and what specific precautions are suggested for your child.

Safety

Keeping your warrior safe during treatment is crucial and can be a difficult task. For osteosarcoma, patient safety generally means keeping them free of germs and protecting the tumor site as it is weak and vulnerable to breaking.

The site of the tumor is vulnerable as the tumor has weakened the bone. Discuss with your medical team if a cast or brace should be worn and if they recommend crutches, wheelchair or walker. Breaking a bone at this point would be very painful and potentially limit choices for surgery. Suggestions to minimize fall risks:

- Use crutches, walker or wheelchair if suggested by your medical team.
- Wearing socks on tile or wood stairs could cause slips and should be avoided.
- Small rugs can easily slip especially in the bathroom and cause a fall.
- Bathtub should have a nonslip mat, chair or similar to keep warrior safe while showering or bathing.

Your warrior will have a severely compromised immune system. Suggestions to avoid exposure to germs:

- Ask any visitors if they have been ill or exposed to someone that is ill. If so, ask them to postpone their visit.
- Everyone should wash their hands with antibacterial soap when they arrive.
- Remove shoes and keep them at the door.
- Use hand-sanitizer when out.
- Be sure food handling minimizes the chance of food spoiling. Food poisoning in an immune compromised person is dangerous.
- If your warrior has a sibling in school where germs are likely, changing clothes and potentially bathing afterschool can help to minimize exposure.
- Cleaning door knobs, light switches, keyboards, handles and other frequently touched part of the home with antibacterial cleanser can help limit spread of germs.

If someone in your immediate family becomes ill, try to keep your warrior from exposure to the germs and consult with your medical team.

Hair Loss

Hair loss is an emotional and difficult part of chemotherapy for many families. For the child, the loss alters their appearance and this is often difficult to handle. Some like to wear hats or scarves while others like wigs. And some rock the bald! Hair loss is a very outward visible side effect that your child is fighting cancer and can be very emotional for all involved.

Families are surprised that for many, hair loss starts weeks after chemotherapy begins, not right away. People report that when they are losing hair it is itchy and their scalp or skin on their arms/legs can hurt. When the scalp begins to hurt, often children find relief when they shave their remaining hair. During MAP chemotherapy most warriors lose every bit of hair on their bodies including eyelashes and eyebrows. This can make their eyes sensitive and prone to irritation from debris. Having some eye re-wetting drops to relieve dryness and help flush debris can be helpful.

Some children love when their friends and family shave with them, and others do not. Talking to your child about what would help them to feel supported and beautiful/handsome is the best method to support them. If your child is attending school, some schools do an event where kids can shave to support their classmate or loosen the “no hat policy” to honor your child. If you are interested there are many wonderful organizations that help with wigs, hats or other items to help with hairloss. Crowns of Courage (www.crownsofcourage.com), makes halo-wigs that are worn under a hat, is one such organization. If your child has not yet lost their own hair, you can have it cut and send to make a halo-wig of their own hair with Crowns of Courage. See their website for additional information.

Hair loss is one of the more difficult side effects for some children and families. Finding the good in it can help you to accept it. Hair cells are fast-growing cells just like cancer cells. Hair loss can be the first visible sign that chemo is killing cells! Plus, chemo can make you tired... so having no hair is one less thing to take care of when you are feeling crummy. Perspective can be everything. While recently, there are some chemotherapy patients that have tried Cold Caps to minimize hair loss we haven't heard this to be helpful with the chemotherapy for osteosarcoma. This may be something to discuss with your medical team.

Thoughts on Chemotherapy From Those That Have Been There

Patient Perspective:

Trish from Orange County, California says, “Don’t fear it. Chemo has a job to do and sometimes we may not like how that job makes us feel.”

Morgan from Montana says, “Everyone is different in regards to what chemo works and how much they can have. While there are protocols for OS, nothing is black and white. I’ve had chemo I handled well and another chemo that I ended up having to stop.”

Emily V. from Wisconsin suggests, “When going through treatments, distract yourself. Don’t fuel the flames of anxiety and depression. Try new hobbies, watch foreign films, do anything and everything that makes you feel wonderful and happy.”

Mary from Minnesota suggests, “Don’t get involved in statistics. They do NOT matter. You or your child/loved one are MORE than a statistic. You are either 100% or not. There is no in between. Go with your gut. There is so much difficulty in OS. SO many things that grab you by the wrist and tell you to do this or that. You are a person first. You are not a patient first. You are part of a family that needs you. The Doctors and Nurses care, certainly, but at the end of the day, THEY are not the ones who will be celebrating or missing your daily presence. This work is hard. Chemo SUCKS. It is brutal at best. But if you put your needs as a SOUL first, you will find your right connections and path.”

Ann from Vermont says, “Hair is a form of self-expression for many. Hair loss should be no different. In a space where I had no control, it felt good to take control of this aspect. Let the patient decide how to handle this.”

Family Perspective:

Maureen from New York said, “There is so little we can do to protect our kids from the effects of diagnosis. Something we can do is to make hospital stays, whether inpatient or outpatient, as easy and as comfortable as possible. For my daughter, it was always about comfortable and pretty. We brought her comforter back and forth with us. We packed pretty smelling body washes and creams - remember taking a shower is sometimes difficult for lots of reasons and being able to offer a soothing, warm, clean

smelling sponge bath is a wonderful gift to be able to share. We packed nightshirts and started the tradition of having a new nightshirt to unwrap after every surgery. We brought in LED candles to place around the room to create a peaceful environment in the evenings when we were watching TV. Greeting cards were encouraged and displayed around the room. We packed a deck of cards and other card games - “What Would You Do?” cards entertained us and the nursing staff! Fake lottery tickets and a whoopie cushion provided moments of unexpected laughter. No matter what we did, we were still in a hospital room but the room became more my child’s personal space than a cold hospital room. All of this gave us something tangible to offer our daughter. It gave her sisters something tangible to offer her when together or to send through the mail when they were away at school. Our goal was to give her things to touch and remember that she was loved and that this too shall pass. The ability to DO something for her was worth all the lugging of stuff back and forth!”

Mum suggests, “Count the rounds down. Accept help from others.”

Liz from Chicago says, “My son could taste medications put into his port. When he was nauseous from chemotherapy it made it all worse. He found different techniques to help - sucking on lemon drops, jolly ranchers or mints, chewing gum or when he couldn’t tolerate anything in his mouth smelling an alcohol wipe - all helped him taste the medication less.”

Jordan from Oklahoma says “Never stop asking questions. Buy a notebook and use it specifically for cancer. Write down every question and every answer because everything is a fog, and you’ll forget the question by the time someone is there to give you an answer. I used my notebook religiously, and it doubled as a journal when I needed to get all my huge, scary feelings out. That notebook was absolutely invaluable.”

Montgomery suggests, “It is a long and hard process but time goes faster than you realize!”

Chapter Two:

TREATMENT

PART B: SURGERY



Included In This Section:

- The Purpose of Surgery
- Testing that could be Helpful in the Future
- Types of BONE Surgeries
- Post-Surgical Needs
- Deciding on Surgical Option
- Types of LUNG Surgeries
- Tumor Testing
- Recovery from Surgery
- Thoughts From Those That Have Been There

The Purpose of Surgery

Surgery is undertaken to remove all signs of disease possible from a patient's body. The rule of thumb in osteosarcoma is that if a tumor can be removed it should be; as survival rates rise dramatically with complete removal of all disease. Occasionally a site of disease will make it unresectable (cannot be removed via surgery due to location or size) then a different approach and protocol will often be considered.

Testing that Could Be Helpful in the Future

Historically, the standard protocol has not included genetically testing osteosarcoma tumors, as the information was not helpful in determining treatment. This is one area that is changing. Doctors have known that osteosarcoma tumors have some of the most diverse genetic mutations among all tumors. This makes them difficult to treat as they all have different mutations that are helping the tumor to grow. This makes targeting a growth pathway difficult, as there are varying pathways for each tumor, even within the same person. The pathways that chemotherapy uses to kill the cancer is better known now, therefore, the specific pathway your child's osteosarcoma is using to grow can potentially offer different or new therapies.

While changing course of treatment is unlikely in frontline treatment; if a relapse occurs tumor genetic tests can offer valuable information. Additionally, current clinical trials seem to be focusing on the type of mutation for enrollment. If this data were available from the primary tumor, this would allow access to potentially targeted trials soon after relapse.

Osteosarcoma tumors offer an additional challenge in that the tumor itself is bone. In order for the pathologist to look at the tumor under the microscope (to assess necrosis and to evaluate surgical margins), the bony tissue must be decalcified using acid. Dissolving the bone in strong acid breaks up the DNA and RNA in the tissue, making it unsuitable for genetic testing. Many families have found that despite a large tumor there are not any cells left untouched by acid and therefore genetic testing can't be done. Methods that work well for genetic testing include: freezing tissue that has not been decalcified or keeping fixed tissue that is decalcified using a gentle acid like EDTA. The issue of decalcification is also important for biopsies and surgery on metastatic tumors. It is possible to reach out to the Pathology Department, either directly or with your oncologist, to ask about their policy for decalcifying osteosarcoma. This is a conversation that many families didn't consider and later in their journey wish they had.

MIB Agents has a **Testing and Research Directory** available at www.MIBagents.org/mib-testing-data-directory-overview. This is a guide to testing and research options to either help inform a personal treatment plan and/or contribute to general osteosarcoma research.

There are two main categories of testing that may provide you with personal results that can inform clinical decision making and a personal treatment plan. The first test for tumor characteristics and drivers. The other is a functional drug test which may test the effectiveness of drugs on cancer cells. Please see the MIB Agents website at www.MIBagents.org for the complete Testing and Research Directory.

Types of BONE Surgeries

As mentioned above, bone surgery is part of most treatment plans to remove the tumor. The goal is to remove the entire tumor and some surrounding tissue (called **margin**) to minimize the chance any tumor cells remain that could cause a recurrence or metastasis. Depending on the

location of the tumor, the surgical options may vary. For tumors in limbs, the options typically fall into three categories: limb-salvage, amputation or rotationplasty. Each has its own pros and cons, but it is very important for a patient, family and the treatment team to thoughtfully discuss surgical options with their orthopedic oncologist. Treatment options are specific to each patient. For most patients, it is legally the parents (and/or guardian) decision which option to choose. When talking with children old enough and mature enough to participate in these discussions, it is helpful in many ways to encourage the patient to help make these difficult choices. The patient is the one who will live with the outcomes and possible limitations of surgical procedures.

Limb-Salvage or Limb-Sparing (LSS):

Limb-Salvage or **limb-sparing** (LSS) is a surgery that removes the cancerous segment of bone and any surrounding tissue that it may be touching. The bone is then replaced with a **cadaver bone** (bone harvested from another part of the body or person) or **endo-prosthetic** (metal parts that are used in place of the bone taken out). The procedure of using a cadaver bone to replace the diseased bone segment is called an **allograft**. The cadaver bone is thought to allow weight bearing sooner and to promote the healing of the harvest bone which is vascularized (blood supply given to the bone) during the surgery.

There are several types of **endo-prosthetics** and the decision of which to select should be made with the orthopedic surgeon. Both types of LSS surgeries- allograft and endo-prosthetic, require long periods of time to heal. Revision surgery(ies) may be necessary for LSS patients to lengthen the prosthetic as the patient grows or to replace/repair parts that may break or wear out over time. New endo-prosthetics are now sometimes being used that can be lengthened slowly using magnets, this may be a possibility to discuss with your orthopedic surgeon depending upon the amount of growth still expected.

When the tumor is in the center of a long bone (rare in osteosarcoma) and the proximal and distal joint are not affected, other surgical methods can be used. One method is called **bone transport** and can be used to regrow the person's own bone over the course of several months.

Amputation:

Amputation may seem like an extreme option but in some cases, it is determined to be the best surgical choice for the patient. There are a variety of reasons that can make amputation the best choice, such as:

- If the surgeon believes they are more likely to get cancer free margins.
- A prior surgery on the tumor or breaking of the bone will sometimes require amputation to be certain all cancerous cells in the area are removed.
- Healing is often faster with amputation compared with LSS (limb salvage surgery).
- When significant growth is anticipated and endo-prosthetic lengthening would not be able to accommodate growth needs.
- Patient would like to continue athletic activities that may be impossible with a LSS limb.
- LSS requires additional surgery(ies) because endo-prosthetic parts wear down and break.

Insurance coverage for prosthetics can be variable and prosthetic limbs and supplies need constant care. These needs and expenses need to be taken into consideration when making your decision.

Rotationplasty:

Rotationplasty is a special type of amputation. Tumors just below or above-the-knee in your femur require an above-knee amputation (AKA). This can make mobility, comfort, and appearance a little more challenging than a below-knee amputation (BKA). Studies indicate that AK amputees require 70% more energy to walk than non-amputees. BK amputees only require 30% more energy to walk. Each joint an amputee is missing requires more energy to become mobile. An AK amputee is missing both knee and ankle while a BK amputee is missing only an ankle.

When a rotationplasty is done, the tumor and associated bone segment along with the knee joint are removed (amputated) and the bottom portion of the leg is reattached. Therefore, rotationplasty is an alternative to losing your knee, as the lower leg, including the foot, is rotated and attached to the remaining upper leg bone. The ankle now becomes a functioning knee joint and a lower leg prosthetic is used to replace the missing portion. The benefits of rotationplasty

are improved function including (generally) fewer future surgeries and decreased or absent phantom limb pain. Rotationplasty can be challenging for some due to the appearance of a backward facing foot where a knee used to be. Many kids who undergo rotationplasty say their appearance is worth increased mobility.

Tumors in other parts of the body may be more difficult to completely remove by surgery, and the reconstructive options may be limited as well. Osteosarcoma can appear in areas like the pelvis, skull, jaw or spine. In many of these areas, surgical options for removal and reconstruction may be limited, and radiation may be added to the overall treatment plan. For these surgeries, it is very important to find an experienced orthopedic surgeon who is an expert with the required procedures. They will be able to offer the best options for potential removal and reconstruction.

Research to improve the surgical options for treating osteosarcoma is ongoing, including new options in prosthetics, both internal and external. Function, mobility and growth challenges are constantly being investigated.

While you have a little time to research and discuss options, your treatment team may encourage and guide you on which decision they believe is right for your child. Remember to get second or third surgical opinions and consider your child's wishes in this decision. Your treatment team does a lot of work behind the scenes once you have made your surgical decisions. Surgery is typically ten to twelve weeks after diagnosis. Your team may need your decision in the first three-or-four weeks post-diagnosis. The eight week period between making your decision and having surgery is needed to prepare for the surgery on their end. Especially for limb salvage, the endo-prosthetic requires time to be custom built to the size of the patient. In addition, due to the complexity of these surgeries, your surgeon wants time to study and prepare for the best approach to maximize the opportunity to remove the entire tumor, with clean margins, while preserving functionality. It is important to understand that these choices need to be examined and decided upon carefully but quickly. Under very difficult circumstances, you must take the time to research the best surgical option for your child and determine the best surgeon(s) to perform the surgery. Often there is more than one surgeon involved in this surgery, an orthopedic surgeon and a plastic surgeon. Once you make your decision, your surgery team

gets busy behind the scenes to coordinate all it takes to be ready by your surgery date.

It is important to note that there are many patients who have a chemotherapy team at one medical facility and a surgical team at a different medical facility. Getting the best team for each portion of the cancer journey will be in the patient's best interest. Many people do not realize that they can look at different teams, doctors and facilities for different procedures.

Post-Surgical Needs

Leg/Pelvis:

- Wheelchair or mobility scooter
- Leg board- attaches to a wheelchair to keep the leg straight and stable
- Ramp for small bumps to get into the house
- Commode (bedside toilet)
- Shower chair
- Ice Packs
- Pillows to prop up leg

Arm/Shoulder:

- Ice packs
- Shower seat
- Recliner Chair with lots of pillows
- Electronic toothbrush
- Bathroom wipes as keeping clean after using the bathroom can be challenging with one arm

Post-surgical needs are real and can be an emotional surrender for a young person to accept using them. It can be a good idea to quietly obtain these items with little fanfare and have them ready when and if they are needed. Often it can be easier for your child to accept the port-a-potty (commode) when he/she really needs it than to be part of the process to acquire one imagining that he/she may need it. Necessity can soften the indignity of relying on equipment you never imagined needing.

Deciding on Surgical Options

The surgical decision can be very overwhelming. Some families (and/or caregivers) have benefited by meeting multiple surgical teams to get various opinions which help them to decide what is best for their patient. Some considerations you may want to discuss:

1. What is the chance of recurrence at the surgical site?
2. What post-surgical mobility limitations will there be?
3. What will be required for physical therapy and regaining mobility?
4. What life-long issues or future surgeries can be expected?
5. What lifelong limitations can be expected?
6. Will he/she be able to jump, run, push, pull, type, write, drive, be independent in the bathroom? What are other important activities to your child?
7. What will the surgical site look like both after surgery and after healing?
8. What assistive devices will be needed (wheelchair, cane, prosthesis, etc.)? How long? Cost?
9. What complications are possible?
10. How many surgeries of this type have you done in the past year?
In your career?
11. What doctor and facility would you suggest getting a second opinion or consult at?
12. What are anticipated pain management needs? What issues are possible for these pain management methods (constipation, addiction, etc.)? What can be done to minimize the issues?
13. Are there pediatric pain management specialists on-site or available for consultation?
14. What are the possible side effect(s) of prolonged pain management?
15. What can be done to mitigate these side effect(s)?



Stories of Surgical Decision Making

The following pages allow a window into other warrior and families surgical decision making process. It is often discussed as one of the most difficult decisions people make in their osteosarcoma journeys. Looking at others stories regarding their decisions after the fact, can give you some indication of benefits and potential pitfalls others have faced.

**Jodi from Michigan's Story:
Parent of daughter with OS in Femur
Researched: LSS, AKA, RP Chose: LSS**

When asked if she felt she had sufficient information to make the decision she wrote: "I do believe we had sufficient info about surgery options. My daughter's oncologist only wants certain treatments and I know there is more out there that would give her better quality of life."

The unanticipated benefits of LSS for her daughter included, "None." The unanticipated drawbacks of RP for her daughter are, "None and hopefully it stays that way."

When asked, in hindsight, do you feel the surgical option was the best choice? Jodi responded, "Yea I do. It has given my daughter hope. It has healed amazingly and is doing well with PT."

Jodi reported that Recovery was technically about a month. Going to PT, walking at home as much as she could, ice and rubbing the bottom of her foot for nerve pain helped in her recovery. Currently she is four months out of surgery and can't run, swim or jump yet.

When asked about activities done since recovery and what activities her daughter is not able to do, Tiffany says, "volleyball and basketball, hiking, dancing, rock wall climbing. She can do all activities, the only thing noticeable is that she runs a bit slower than she did prior to rotationplasty and fatigues more easily due to the energy required. But she has no limitations."

Tiffany's suggestion for parents and warriors currently making surgical choices: "Make sure you weigh all options and make a decision that is best for you/your child. Remember all children are different."



**Rindy from North Carolina's Story:
Warrior with OS in Tibia
Researched: LSS, amputation Chose: amputation**

When asked if she felt she had sufficient information to make the decision she wrote: "I feel like I had all the information I needed to make my decision. I first recommend identifying your goal in outcome. My goal was to be more active, so amputation was the obvious choice for me. If someone isn't active or doesn't care to run, jump, etc. then limb

salvage may be the right choice. One should ask about anticipated return to usual activity, likelihood of having revision surgeries in the future, and most importantly, which option do they feel most confident in getting all of tumor out with negative margins. My tumor was on my distal tibia (near the ankle), so my amputation was below the knee. This made amputation an easier choice as below knee amputees can be highly active. Had my tumor been in the typical location around the knee I likely would have chosen LSS because rehab for an above knee amputation is much more difficult.”

The unanticipated benefits of amputation included, “I returned to normal activity rather quickly. I was able to start jogging after 1 year and now have an actual running blade.”

The unanticipated drawbacks she has found of her amputation are, “Not having a leg on all the time. There have been times when I have my leg off to let it breathe and I forget that it is off because I’m so used to it and the phantom sensations make it feel like my leg is still intact. I’ve stood up quickly to get my toddler to stop doing something and have fallen as a result. Also, prosthetics are expensive. I have great insurance and haven’t had to pay for any of my legs, but seeing the bill was shocking.”

When asked, in hindsight, do you feel the surgical option was the best choice? Rindy responded, “Yes! I’m able to do everything I want to do. Also, my smallest margin was 4cm, so I have total peace of mind that they got all of the cancer.”

Rindy was asked about recovery and milestone, she said, “I think I’m still in the recovery period (1.5 years post-amputation). Regarding surgical recovery, I was able to drive myself to Target and shop by myself 2 weeks after surgery. 6 weeks post-op I was casted for my first prosthetic and started testing sockets. I received my first “take home” leg [approximately 15 months after amputation] and within 3 weeks I was walking without any assistance.”

When asked about activities done since recovery, Rindy says, “I walked all over Disney World, go to the gym regularly, starting to train for a 5k, and was certified as a scuba diver.”

**Tiffany from Atlanta's Story:
Parent of daughter with OS in Femur
Researched: LSS, AKA, RP Chose: RP**

When asked if she felt she had sufficient information to make the decision she wrote: "Yes, but only because we sought out the information for ourselves. I would recommend a newly diagnosed patient interview multiple surgeons, but then also speak with patients and physical therapists, because they do a much better job of presenting the realistic pros and cons of each option."

The unanticipated benefits of RP for her daughter included, "It has allowed her to be active in more ways than we even considered...not just sports, but things like hiking, plying in the ocean, dancing in school musicals, jumping on trampolines, etc. Additionally, one surgery and done...she was able to get back to life without facing multiple surgeries, time out of school, months with no weight bearing, etc."

The unanticipated drawbacks of RP for her daughter are, "Prosthetics can be frustrating and time consuming...getting the right one for the best performance, endurance, appointments, etc. Many amusement and water parks have rules regarding amputees...that has been a bit difficult to navigate."

When asked, in hindsight, do you feel the surgical option was the best choice? Tiffany responded, "Absolutely. Our daughter had a rotationplasty at 10 and is now 17 and says it was absolutely correct and she would not change a thing."

Tiffany reported that her warrior didn't have any complications and recovery was approximately three months. Finishing chemo was the key to recovery, it was hard to heal and get stronger during chemo. A good PT (physical therapist) and a good prosthetist was important.

When asked about activities done since recovery and what activities her daughter is not able to do, Tiffany says, "volleyball and basketball, hiking, dancing, rock wall climbing. She can do all activities, the only thing noticeable is that she runs a bit slower than she did prior to rotationplasty and fatigues more easily due to the energy required. But she has no limitations."

Tiffany's suggestion for parents and warriors currently making surgical choices: "Gather as much information from as many different sources as possible...kids know what they want, allow them to make the decision...even though it's hard, do not simply listen to the advice of one surgeon, they all have their own bent...do your own research, find people who are living with the "after" of each choice."

Karen B.'s Story:
Parent of son with OS in Femur
Researched: LSS Chose: LSS then RP

When asked if she felt she had sufficient information to make the decision she wrote: "No. LSS was presented as a panacea- no complications and a guarantee that my son would be able to run one day. Rotationplasty was presented as a disfiguring solution. Rotationplasty was suggested in a whisper by a second opinion doctor."

When asked about unanticipated benefits of LSS for her son she reported, "None, there were complications right away."

The unanticipated drawbacks of LSS for her son were, "Severe nerve pain, infection, scar tissue build up and torn patella. The prosthesis had to be replaced and then five years later, rotationplasty."

When asked, in hindsight, do you feel the surgical option was the best choice? Why or Why not? Karen responded, "No. Our goal was first to remove the tumor and second for our son to return to as athletic a lifestyle as possible. Rotationplasty is a far better choice for athletes. If the doctors had taken the time to explain rotationplasty better, we would have chosen it."

Karen's suggestion for parents and warriors currently making surgical choices: "The reason that doctors gave us against rotationplasty was "you will have to use crutches when you wake up every morning" and for some that is significant. But if the tradeoff is only one surgery and the ability to run, rotationplasty or amputation might be worth it. Doctors usually assume they know what is best, but they are not infallible."



Liz's Story:
Parent of son with OS in Femur
Researched: LSS, amputation
Chose: amputation (knee disarticulation or thru-knee)

When asked if she felt she had sufficient information to make the decision she wrote: "Yes and no. We didn't know that rotationplasty was a potential surgical choice for osteosarcoma. Our surgeon didn't discuss it and we didn't know to ask. Likely it wouldn't have changed our decision for traditional amputation but it would have been nice to hear about this as a potential option when we were deciding."

The unanticipated benefits of amputation included, “Having the certainty that they got out all the cancer in the area. Also, we appreciated that it was one surgery and done, with LSS there would have been additional surgeries to keep the endo-prosthetics in working order. Our son was able to have a thru-knee amputation which removed his entire tibia but kept his femur intact. This requires a prosthetic knee but allows his femur to bear direct weight, which most above knee amputees cannot do. This has been helpful for bone strength, non-weight bearing bones can slowly lose strength and some function of muscles that would otherwise be impacted.”

The unanticipated drawbacks of amputation, “We didn’t realize that his residual limb would change a great deal in the first couple of years and require lots of time in the prosthetists office making new sockets. That being said; it is easier to deal with maintenance issues when all the prosthetics are on the outside and can be removed and fixed without surgery. With a thru-knee amputation his amputated knee is significantly longer (as it is a prosthetic) so modifications have been necessary for bike riding and a few other sports.”

When asked, in hindsight, do you feel the surgical option was the best choice? Liz responded, “Yes. Our son has resumed all activities and maintained a very active lifestyle. He chose this surgery and is pleased with the outcome, in the end that is what matters most.”

Liz reported that her son had some problems with significant phantom pain about a week after surgery. This was scary but became tolerable after a medication change and techniques to help his nerves adjust to the loss.

When asked about activities done since recovery and what activities her son is not able to do, Liz says, “The lack of limitations is what helped our son decide on amputation. There are some activities that require practice and a modification but he has found a way to do everything he wants to.”

Liz’s suggestion for parents and warriors currently making surgical choices: “Ask a million questions about each option. We considered trying LSS first and then going to amputation if it didn’t work but our surgeon discussed the likelihood that this would be a higher amputation. With all the possibilities, issues, pros and cons we felt like our son chose the best option for him. But if we hadn’t gone through ‘what-if’ questions with our surgeons we likely would be in a different spot.”

Allie's Story:
Warrior with OS in Femur
Researched: LSS Chose: LSS

When asked if she felt she had sufficient information to make her surgery decision she wrote: "I didn't have many options - ended up having a total hip, femur, and knee replacement (all on right leg). I personally didn't have many options (if any) due to certain circumstances of my case (i.e. aggressiveness of tumor and how much it had already spread at time of diagnosis, etc.) - if I had to recommend anything when it comes to surgery for any current and/or future patients, I'd say don't be afraid to ask questions and even get a second, third, etc. opinion from other doctors to see what other options there may be or to confirm the suggested plan presented to you."

The unanticipated benefits of Allie's surgery included, "Even though a lot of muscle was removed along with the obvious bone removal, I have been able to stay healthy and in shape finding different ways to stay fit."

The unanticipated drawbacks of Allie's LSS are, "A lot of post chemotherapy surgeries due to pain, leg growth (causing leg length discrepancy), chronic pain."

When asked, in hindsight, do you feel the surgical option was the best choice? Allie responded, "Yes - again, I didn't have many options if any but would choose the same option today if I was presented with that choice now. Even though I'm in pain often and have had almost a dozen surgeries since 2011, I still was able to keep my leg and workout heavily in the gym and biking."

Recovery for Allie was, "Long for sure - I was struggling post-surgery due to aggressive chemotherapy that really made me weak. With the severity of my surgery(ies), recovery is forever. I have to constantly stay healthy and workout consistently to keep my leg strong and maintain strength of whatever muscles I do have left. Milestones are seemingly minuscule when looking back but at the time they were major, starting from the flexion and extension of my knee, to lifting the leg up entirely, hip restrictions (i.e. leaning forward past 90°), switching from wheelchair to crutches and from crutches to a cane and of course cane to nothing!"

When asked about activities done since recovery Allie says, "Every exercise counts. Even if it seems silly or minuscule, even if it's a few leg lifts, it is all crucial to recovery, whether you think so or not. Consistency is key. Do what you can when you feel up to it and don't push yourself too much. Try to set very small- and most importantly- attainable goals, daily and longer-term goals - it helps keep you on track."

Types of LUNG Surgeries

The lungs are the most common location for osteosarcoma to metastasize. Similar to primary tumor location the treatment is usually a combination of chemotherapy and surgery to remove the tumor(s). There are a couple different types of surgical procedures used to remove osteosarcoma from the lungs.

- Thoracotomy
- Thoracoscopy (sometimes called VATS)

Thoracotomy:

A **thoracotomy** is an invasive surgical procedure that allows the surgeon to deflate the lung(s) and manually palpate the lung tissue with her/ his fingers to find nodules in the thoracic cavity. While it is more invasive, it is often seen as the preferable surgery as a surgeon can find and remove more nodules than are visually seen on a CT scan or through a thoracoscopy. Removing more nodules has the potential to decrease additional disease being found after surgery.

Thoracoscopy (VATS):

Thoracoscopy/pleuroscopy is a minimally invasive procedure that allows access to the lungs or pleural space using a combination of viewing and working instruments (clamps, scalpels, etc.). It allows for internal examination, biopsy, and/or resection of disease or masses within the pleural cavity and thoracic (lung) cavity. Thoracoscopy may be performed either under general anesthesia or under sedation with local anesthetic.

Video-assisted thoracoscopic surgery (**VATS**) is a type of thoracic surgery performed using a small video camera that is introduced into the patient's chest via small incisions. The surgeon is able to view the instruments that are being used along with the anatomy on which the surgeon is operating.

Tumor Testing

Tumors can be tested for genetic changes that may inform care. All tumor tissue goes to the pathology department. As discussed earlier in this chapter; current standard pathology protocols often decalcify the tumor tissue with strong acid. Unfortunately, once a tumor has been decalcified, it cannot be genetically tested as the DNA has been damaged by the acid

in the decalcification process. Therefore, changing these protocols may be best to save some tumor in its natural (calcified state) in the freezer, or processed with gentle decalcification techniques, which allows for genetic testing at this point or a future date if relapse occurs. Preserving tissue with intact DNA and RNA is also an important avenue for researchers to learn more about osteosarcoma to help future patients. The goal of testing tumor tissue is to identify genetic changes that are present only in the tumor cells and is different from testing for familial, or germline, gene changes that run-in families. Genetic testing can take significant time- four to eight weeks, so determining the best time to pursue genetic testing should include this information. See www.MIBagents.org for the Testing and Research Directory for specific information.

Recovery From Surgery

Recovery time from any osteosarcoma surgery is significant. Generally, surgeons will have to determine when enough recovery has taken place to restart chemotherapy. Chemotherapy is a life-saving treatment, yet can slow down recovery from surgery. It is a delicate balance determining how long to heal from surgery without allowing new disease to grow before resuming chemo. Management of pain, beginning movement and physical therapy can all be very draining and time-consuming. Remember that focus during this time should be on recovery and healing-socialization, school, and activities, while important, should be seen as second to rest and recovery.

Listen to your doctor- this is a very unique surgery; it is not similar to a knee or shoulder replacement. Your child's needs for mobility and physical therapy will be significant. Being sure to gain mobility and weight bearing at appropriate times to maximize mobility while minimizing potential injury is crucial.

Thoughts About Surgery From Those That Have Been There – “I Wish I Knew”

Patient Perspective:

Trish from Orange County, California says, “Surgery, for the most part, is easy. The hard part is the recovery.”

Morgan from Montana says, “Surgery is a tough time decision no matter what you opt for. I had a rotationplasty at age 5 and am 100% sure it was the right choice for me. Keyword being “me”. Everyone is different, weigh the options and go with what will let you be you in the short term but also long term.”

Mary from Minnesota says, “Make sure you know all of your options. Doctors will tell you what they believe is best, but it may not be best for YOU. Don’t do something just because you were told to. Ask questions. Again, you are YOU.”

Family Perspective:

Cate from Chicago suggests, “Surgery is a major part of saving the life of your OsteoWarrior. No matter what challenges surgery may bring, your family WILL find a new normal and be able to thrive.”

Mom from Long Island recalls “Our beloved prosthetist told my daughter that kids are going to stare at her after her amputation. They are going to ask questions about what happened. Then he paused and said ‘the kid who doesn’t look at you or ask a question is st*^pid! How could a smart kid not wonder what happened to your leg?’ That perspective gave my daughter patience and fortitude in staying calm when a young boy looking at her amputated leg asked her what happened to her foot! Sometimes life gives us a good laugh too. And we don’t use the word stupid in our home but in this case, it fits.”

Cate from Chicago says, “Educate yourselves on all available surgical options for your Warrior and then see your surgeon as soon as possible. Make sure your surgeon will discuss the pros and cons of each option so that you can make the best choice for your family. Unfortunately, sometimes surgeons only offer the surgery they prefer, but that might not be the best option for your family.”

Chapter Two: TREATMENT

PART C: POST-SURGICAL CHEMO Adjuvant Chemotherapy



Included In This Section:

- The Purpose of Chemotherapy after Surgery
- Continuing Chemotherapy after Surgery
- Change in Cisplatin in the COG Protocol
- Expectations as Therapy Continues
- Thoughts From Those That Have Been There

The Purpose of Chemotherapy after Surgery

Chemotherapy after surgery is called **adjuvant chemotherapy**. This chemotherapy is used to continue killing any osteosarcoma cells that may be left and too small to identify in the body after surgery. These cells could remain due to poor margins or cells that have gotten into the blood or lymphatic system. These microscopic cells called **micrometastases** are present in the majority of patients at the time of diagnosis and circulate to other parts of the body via the bloodstream. These micrometastatic cells cannot be detected on scans or through common blood work (although currently researchers are trying to make advances in this). The adjuvant chemotherapy is used to kill these cells and prevent any further metastasis or recurrence from happening.

Continuing Chemotherapy after Surgery

Osteosarcoma is a cancer that is known to have micrometastasis in most cases. As cited in the article “The Effect of Adjuvant Chemotherapy on Relapse-Free Survival in Patients with Osteosarcoma of the Extremity” by Link et. al in The New England Journal of Medicine, June 1986, prior to chemotherapy being used in osteosarcoma 80% of patients relapsed post-surgery indicating undetectable but present metastatic disease. Many

studies have been done to determine the chemotherapy regimen best suited to disease-free survival while minimizing long-term impact from therapy. This indicates there are malignant cells present that cannot be detected that grow into new tumors without chemotherapy post surgery. Adjuvant therapy is the best hope to kill these nasty suckers before they have a chance to form a tumor. The chemotherapy of osteosarcoma is tough, really tough, but killing all the cancer the first time is of utmost importance as each relapse becomes harder to treat.

Change in Cisplatin in the COG Protocol

Many cancer therapies have a maximum dose. Larger doses generally have less acceptable risks to the patient than the benefit the therapy provides. After 4 full-strength doses of cisplatin, the maximum dose is generally reached for that patient. Throughout treatment you may be faced with other ‘risk vs. benefit’ discussions - this is a discussion where you examine the potential risks (side effect) of treatment compared to the potential benefits of a treatment. The benefit should always outweigh the risk. Remember that the COG protocol is a suggestion and doctors will often modify as needed for a particular situation or patient. Always ask questions, this is your body and your treatment, you should always be a part of the decision-making.

Expectations as Therapy Continues

Treating and beating osteosarcoma is a marathon, not a sprint. There are highs and lows, ups and downs. Many patients experience more fatigue as therapy continues and their body is exposed to more chemotherapy. There can be more delays due to low blood counts from the ongoing chemotherapy. But patients and their team also get better at knowing which medications help combat the side effects for each individual. Staying as nourished, hydrated, rested, involved, engaged and as healthy as possible is difficult but should be your highest priority during this challenging time. Help your child remain a kid, feel loved, cared about and important throughout treatment. How your child endures treatment impacts how your child will be prepared to move on after treatment.

Thoughts About Post-Surgical Chemo From Those That Have Been There – “I Wish I Knew”

Patient Perspective:

Morgan from Montana suggests, “Chemo sucks. I’m not going to sugar coat it. The farther I got into chemo treatment, the harder each round got physically and mentally. I don’t want to lie and say it’s going to be fun. I think going into chemo you need to be realistic so that you don’t get blindsided by the effects of it. At the same time, being super anxious will make it worse. It’s a balance. I decided upon my 3rd relapse that I was done with cancer controlling my life. I went into treatments with the mentality of them being an item on my to-do list instead of being the entire to-do list. By not making cancer the focus I was able to have moments that weren’t always based on medical stuff.”

Sloane from Chicago says, “Chemo is hard and can put a family through a lot of stress and pain. But when you make the most of those days in the hospital they go past a lot quicker. When you play games instead of staring at the television, or talking instead of spacing out it makes it seem as though the day is going by much faster than before. Another thing is that walking helps keep you more awake and helps you feel a lot better. Kids usually don’t like this at all, coming from one who really disliked walking the halls of the hospital. But it always made me feel better even if I didn’t want to acknowledge it.”

Amanda from New Jersey says, “The horrible feelings you may have during chemo are temporary. Believe the awful sickness and pain is occurring as a POSSIBLE side effect of what the chemo MAY do to us, imagine and feel the deadly effects it’s SUPPOSED TO DO on those disgusting cancer cells trying to hurt us!”

Amanda from New Jersey also says, “Even though you’re going through a very difficult time, you will smile. Make sure you smile, really smile, because “happiness” is the very best medicine. Stay strong and believe!”

Family Perspective:

Cate from Chicago says, “Chemo sucks. You will never like it but you will find a way through.”

Gracie from Conyers, Georgia says, “FIGHT, FAITH, AND FINISH.”

Cate from Chicago adds, “Be patient. Take notes so that you can identify patterns and create mechanisms to make the next chemo(s) go more smoothly. It is a good way to focus on things you can do to help your Warrior through.”

Linda from Pennsylvania says “Chemo after surgery was much harder. In part because of the physical limitations but in part because of the opioid painkillers. What no one seemed to know was the opioids can make nausea worse. This is just something to keep in mind as the medical personnel tried to convince us it was anxiety and other related conditions. I finally made the connection right about the time my son tapered down on the opioids and when he discontinued them completely his nausea improved greatly.”

Chapter Three: END OF PROTOCOL



Included In This Chapter:

- The Protocol is Done
- Recovery from Chemo
- My Status
- The New Normal
- Challenges Post-Treatment
- Returning to a World Not Focused on Cancer
- Thoughts From Those That Have Been There

The Protocol is Done

Congratulations! You have finished the protocol. Your cancer journey may not be finished but you deserve to celebrate the completion of such a grueling time... celebrate! Generally, final scans will be done sometime within the month or two after therapy ends to determine if any disease is still present. If disease is not found then a schedule of scanning and check-ups will be discussed to be sure that any potential late effects from therapy or relapse are caught and dealt with quickly. The specifics of this schedule seem to vary by doctor and hospital, so work with your team to define and understand the schedule of follow up recommended for your patient. It is okay to ask why they include or exclude certain types of tests. This can vary based on specifics of your patient's diagnosis and case, to philosophies of the specific hospital or doctor. If new disease, recurrent disease, or additional disease is found then a new plan of action will be developed.

Recovery from Chemotherapy

Patients and parents (and/or caregivers) are often surprised at the length of time it takes for the body to recover from chemo and surgeries. Fatigue, memory issues, recovery of the immune system and mobility takes much longer after treatment ends than most people imagine. Each

person is also so different, anticipating how long recovery will take is nearly impossible. Know that many things will recover, you have been through a very challenging set of treatments- you are a changed person both physically and mentally. You may have a new appreciation for the joys of life and love. Revel in that new perspective and be patient with yourself as you recover. Fear of relapse and survivor's guilt is almost universal, counseling and talking about these feelings can often help as these are normal, but you do not want them to interfere with enjoying the life you have fought so hard to have. Physical therapy can intensify now that your nutrition and strength will improve. Take time to heal both physically and emotionally, you may not even realize the depth of trauma you have gone through. Getting additional physical therapy, reestablishing connections with family and friends, increasing time with a counselor or therapist and truly resting is absolutely crucial to starting your post-cancer life in a positive direction. As the physical challenges of treatment decrease or end, the emotional challenges often begin. Do not underestimate the difficult feelings and emotions that will likely surface. To move forward, you must work to understand and work through these emotions. Most warriors and family members find that help from a counselor, social worker or therapist is very helpful.

My Status

If your scans remain clear of disease, your doctor will refer to you as NED - no evidence of disease or NERD - no evidence of recurrent disease. This is the best kind of NERD to be!

Recurrent disease describes when treatment has not completely eradicated your disease and relapse describes when the disease has developed in a new location in your patient's body.

My New Normal

Many cancer survivors describe their life as before and after their cancer diagnosis. Treatment is demanding, scary, and all-consuming but can lead you to a new appreciation of the world and your place in it. That being said a new normal has to be established.

Routines, relationships, goals, and yes, even giving and receiving discipline again must be re-established. Exciting things happen to your patient's body. Hair starts to grow back. It can grow back differently in color, thickness, and texture. Strength and endurance rebuild as your patient's

blood count returns to normal and atrophied muscles strengthen, this can be slower for some than others but develops steadily over time. As the body begins to heal your patient will see more benefit from physical therapy. Ease of mobility can increase. Flexibility will return. But you will see them return with practice and work. Your patient will learn to get the most out of their prosthetics, both internal and external, and learn to understand the limitations of them. Pay attention to your patient's abilities without trying to compare him/her to before, or to a friend you made during treatment. Increases in strength, mobility and flexibility can take great effort and patience. Celebrate achievements because often we can expect that these return quickly and they don't. Recovery requires a great deal of commitment from your warrior.

Pain has been an ongoing issue for many patients throughout treatment and can remain chronic in recovery. It is important to work effectively with a pain management specialist. If you have a pediatric patient it is important to work with someone who understands pediatric pain management and how to discontinue pain management medications. It is also important to work with someone who can help you determine what pain needs to be treated with pain medication and what pain has to learn to be tolerated. A sad reality is some OS survivors will have to learn to live with chronic pain. Once treatment is completed, all pain may not be negated through opioid use, and dependence on opioids is not likely to be in your child's best interest. There are times all pain cannot be eliminated. That reality is not limited to cancer survivors, many people learn to live full lives with chronic pain.

Emotions can sometimes be harder to heal than the body. Emotions can fluctuate more now than during treatment. Patients have to accept altered bodies, relationships that may have changed while they were fighting for their lives, and begin to process what they have lived through. Being a teenager is always challenging. Being a teenager who has to navigate recovery can be even more challenging. It can be hard to balance being "happy to be alive" with "angry" that their best friend or boyfriend has replaced them. It can be hard to accept they can no longer play the sport they loved. Recovery is filled with things to be grateful for and things to be really upset about. Be kind to them. Be patient with them. Love them through their moods while expecting them to be productive. Help them be kind and loving toward themselves while they regain their place in the world. When the struggles become too great to handle on their own

or within your family, seek out a therapist experienced with the world of cancer. A parent consult with such therapist experienced with the world of cancer can leave you assured that your patient is doing as well as expected, can offer you suggestions to support them through recovery or could be the beginning therapy for the whole family as you learn to be you again. Therapy can be short term or take a while. You will know what is best for your family.

There is a delicate balance in giving your patient, yourself, and your family time to heal without crossing over to a period of stagnating; of not growing or moving past issues that are holding you back. If you see anyone in your family struggling with reclaiming their new normal address it, talk about it and seek out someone to help you heal in all ways - medical or emotional. Recovery is about healing body and soul. You all deserve it.



Challenges Post-Treatment

While the end-of-treatment is a key milestone and one to be celebrated, it can be difficult.

Emotional:

For patients, ending treatment involves learning what life after cancer is. That includes understanding the follow-ups required to make sure cancer is not returning. What are these tests and why are they necessary? Survivors just spent a year in and around the hospital more often than not, starting to move past treatment requires a new mindset and changing priorities. It can be an exciting but also challenging time as a new normal needs to be established.

Treatment may have created a new circle of friends. Know that post-treatment these friendships may be difficult to keep up with. These are friends that share a common experience that others can't fill or share. It can be good to seek out support groups or foundations with activities that include survivors. It may be challenging for you, as you recover, to spend time with a friend who is still in treatment. There may be a distance between you that was not there before. This is understandable. Respect the awkward and give yourself time to consider what is causing it. Your friendship is something that you can return to as time moves on. Like treatment, nothing is forever.

It can even be challenging for parents or caregivers as well. Over the past year, you have been totally focused on treatment almost every day and had the doctors and hospital staff to work with. Post-treatment, is similar to that first day they were sent home after having a baby. You are on your own and may be wondering what the heck you are supposed to do next. Things change from, planning around how many days we are in the hospital this week, to waiting for weeks or months for that next doctor appointment or test. For some the feeling of “we should be doing something more” sets in. The financial and relationship strains that have likely been glossed over until this point suddenly require attention. Dealing with bills and mounting debt can be overwhelming. Trying to navigate your roles as partner/wife/husband and possibly parent to other children need time and space to reach a new normal. Similar to survivors, it is good for parents to seek out or continue participating in support groups or counseling.

Physical/Pain:

For patients, the physical recovery can take significantly longer than they anticipate. Physical mobility often needs to be continually worked at with physical therapy. It is important to understand that healing is slowed or compromised during chemo treatments. The slow crawling pace of learning to move with new parts, scar tissue, and muscle loss can be frustrating but with consistent and dedicated effort you will see an increase in mobility and body strength. When physical therapy can be more intensive after chemotherapy is finished often additional pain control methods and rest will also be required to help the body heal and strengthen.

Returning to a World Not Focused on Cancer

During recovery, osteosarcoma may still be a central focus to your life. Life is filled with doctor appointments, scans, learning to live with the side effects of treatment and perhaps dealing with a surprise side effect months after treatment. For many the worry about a recurrence is difficult to navigate. While juggling all of this you have to transition back to non-cancer focused activities like school, work, fun, social events, finding time to pay bills and fix household projects that have been on hold. Moving from the world of cancer back to the non-cancer world is important for the patient and the family. You likely found social relationships have changed. Some people you thought would be with

you through thick and thin were absent, and others that were mere acquaintances suddenly became your biggest advocates and supporters. This will be similar for your osteo kid, you and your family. Each person navigates this differently and often some type of counseling or therapy can help each person to understand the difficulties of this transition and how to best navigate what can be a bumpy road. Another complication on the road to recovery is that your patient may look ‘fine’ to the rest of the world while only those really close to him/her can ‘see’ how not fine they are. Try to take a breath when the world is expecting more from you and yours than is possible. Consider talking about the challenges of recovery to those outside your immediate circle. A little information can help (re)build relationships and school/work expectations too.

There is a difference between worry and anxiety. Worry is what happens when faced with a stressful, awkward or potentially dangerous situation. But you can cope and flourish through worry. Anxiety is when worry becomes so great it is unmanageable and interferes with your life. When this happens, it is a good time to check in with a therapist so you can get your anxiety under control and continue along the road to recovery. Anxiety around scan times is real and dubbed ‘scanxiety’ in the cancer world. For most, it is a very real and scary time. Our fears creep into our thoughts and dreams. Learning ways of handling these stressors will help you and everyone in your family. Unfortunately, without good coping strategies, we can unintentionally hurt our personal and professional relationships. A social worker or therapist can help you and your family develop coping strategies and methods to deal with these difficult times.

Many find that slowly adding in activities, work and school help them to emotionally move forward while others like to make the jump all at once; unfortunately, there isn’t a best way, only a way that you will find best for you.

Thoughts About Post-Treatment From Those That Have Been There – “I Wish I Knew”

Patient Perspective:

Amanda from New York says, “Finally the end is in sight!!! After all these months of being cared for by doctors, nurses, therapists and everyone on a daily basis, it stops. Be aware that the end of your protocol, something you have looked forward to for SO long, may be as scary (or even scarier) than when you were first diagnosed. You’re on your own and will not be seeing everyone you saw every day taking care of you and making sure all your levels were ok, your scars healing properly, etc. You have a new life after treatment ends...it is scary, but enjoy it and live every day as a gift.”

Amanda from New Jersey suggests, “I hope you have scanxiety forever. It is real and can be crippling, but remember you’re not sick until you’re told you’re sick. Try to not think about what could be (I know, unrealistic). Give yourself a day or two to worry, that’s all. Try it!”

Family Perspective:

Linda from Pennsylvania says “A family friend who is an oncologist says that he has found it takes at least 2 years before his patients return to a new normal”. It’s hard to live life now, play catch up with what didn’t get done during treatment and move forward. Be patient with yourself and be sure to build in good self-care routines like exercise, yoga, time doing what you love, etc.

Ashley from California suggests, “We felt as if we were left to fend for ourselves. There wasn’t any guidance on who our primary contact would be or what services were available to help us transition. Since we were no longer “in shock” with diagnosis and we were very familiar with the hospital and staff it felt lonely to go back to “normal”. We found the counseling dept. at our hospital to be insufficient. They didn’t know our case at all even though it was with the same hospital. We sought outside counseling and physical therapies. A book or pamphlet on how to transition would have been helpful even if it was just to know someone thought about it.”

Ashley from California also suggests, “Get to know your radiology department. We always had speedy scans and with people my son knew very well. They knew what to ask and what not to ask and we always were confident that someone knew we were coming in and would be smiling at us when we did. We also alerted Child Life services to check in each time we had a scan.”

Chapter Four: COPING, LIFE POST-TREATMENT & RELAPSE



Included In This Chapter:

Needs of the Caretaker
Second Opinions and Evaluating Treatment Options for Relapse
Dealing with Side Effects
Coping- Patient, Parent, Caregiver and Sibling
Challenges Post-Treatment
Balancing Work and Treatments
Changes in Relationships
Relapse
How your Support Team Can Help
Future Treatment Options
Thoughts From Those That Have Been There

Needs of the Caretaker

As the needs of your child are so overwhelming, your individual needs often take a very low priority. While this is understandable, it is not sustainable through the entire treatment without burning out or leaving you susceptible to physical and mental exhaustion. You may get offers to help; accept a caretaker reprieve while a friend or family member stays with your child. Some options for caretaker “breaks”:

- Meditation (can be done anywhere while the patient is resting)
- Journal writing
- Yoga
- Coloring
- Massage or manicure appointment
- Coffee or tea with friends
- Computer or phone games
- Exercise
- Cards
- Dinner with friends/ family
- Counseling

- Reading a book unrelated to cancer or self-help
- Reading an entertainment or gossip magazine
- Seeing a movie

As a caregiver, if your emotional well is empty, you will have nothing to give your child. Taking care of yourself is an important part of the journey that needs to be included. Especially in the early days following diagnosis or surgeries; caregivers tend to neglect themselves. Don't forget to eat and sleep. You need to be there for your patient, and that means actually being there. It is important to remain alert and able to understand what doctors are saying and to be able to respond to the needs of your patient.

As time goes on, you need to find ways to take care of yourself so that you are not only there for your patient, but also your spouse and other children. This can be tricky to juggle. It is crucial to maintaining healthy and strong relationships with your family. This balance can positively affect your child's journey through treatment and recovery too. If you can't take care of you for you, consider taking care of you for them! Don't forget that you too need to return to the world without cancer when this journey is over. Try to remain involved with your friends so they are there when you return to the real world during recovery.



Second Opinions and Evaluating Treatment Options for Relapse

Common sense tells us that any serious illness or surgery should include a second or multiple opinions. With an osteosarcoma diagnosis, it is paramount that treatment begins quickly. Once you are confident in the diagnosis how do you balance the need to begin treatment with the time to get a second opinion?

First, take some comfort that the MAP treatment protocol is the same everywhere. It is surgical procedures that offer options, and you will have some time to consider these choices before making a decision. While the MAP protocol is sometimes modified, generally it is not changed until something indicates a need for it to change. Getting second opinions, while beginning treatment is possible.

Getting a second opinions in a timely manner is possible. If you live in a

highly populated area you can consult with another large hospital in your area, preferably a sarcoma center. Many treatment centers offer remote appointments meaning you do not have to physically go there. Your treatment team/hospital can send all lab work, scans, pathology report, etc. to your second opinion doctor. You can then have an 'electronic appointment' through a conference call or skype. Please remember that no information can be shared about your patient without your signing a Release of Information.

When doctors present treatment plans, families can feel overwhelmed by the enormity of making decisions. Most doctors/COG treatment centers offer MAP as the chemo protocol - not much choice here, but some places do deviate slightly in their chemo protocols. Non-COG treatment centers don't follow the same exact guidelines that COG recommends but the treatment here is still pretty standard. When an initial response to chemo is not favorable, as hoped, changes in chemo can be made to try to increase response rate. Ifosfamide and Etoposide (IE) are generally the second chemotherapies currently used but genetic testing may indicate a different alternative.

Surgery offers options. It is important to understand how different teams come up with different options. You will need information to weigh those options to choose the best one for your patient.

Ask questions. Understand the information as best you can. Talk to your patient and family. Often a determining factor is 'fit' - how comfortable you are with the treatment team and facility. It is important to understand the different choices and methods proposed for chemo and surgery. When you have some understanding of how different teams come up with the same or different options, you will be able to weigh these opinions and choose the best one for your patient and family.

Dealing With Side Effects

Side effects from chemotherapy and surgery are daunting. Doctors have a large arsenal of medications that can be used to combat these side-effects. While your child may have brief periods where they really feel crummy, they should not be miserable throughout this grueling treatment. Often parents (and/or caregivers) first thought is to give their patient anything and everything to eliminate pain and nausea. The reality is, this is not possible or good for your warrior. The goal is to limit pain and nausea as

much as possible! Medications exist for this purpose. But all medications have side effects and they should be considered carefully. Pain medication side effects include severe constipation, nausea and the risk of addiction. When it comes to pain medications, you will need to navigate the balance between mitigating pain and the side effects of the medications. If additional pain medication is causing nausea and constipation, then you will need to add even more medication to alleviate those side effects; you can see how this cycle of medication on top of medication can be challenging and cause confusion.

Each patient has a different response to a given medication. If one doesn't seem to work, approach your team with your observations and concerns. They may be able to change the dose or suggest a new medication. Pay attention to your child, not only what the listed side effects are of a medication. Some medications may warn of sleepiness yet your child can't sleep while taking it. Insomnia is always problematic but is not optimal during chemo when your body is working so hard, rest is healing and restorative.

The key point is to mitigate suffering whenever possible. Chemo and surgery recovery are not pleasant but there are medications to help relieve the worst of the side effects. Medication management does require patience and time to tweak the 'cocktail' to make it work for your patient. Alternative therapies are also resources to investigate such as: nutrition, guided imagery, meditation, yoga, and massage these can all be useful in fighting nausea and pain. As with all things, you must be open to exploring these options. As with school work, 'buy-in' is important to finding these interventions productive. You can't force a young person to benefit from meditation or a healthy diet if they don't want to try it. Talk to your doctors or the palliative care team (this team focuses on hard-to-treat pain and discomfort, not only end of life issues).

Coping- Patient, Parent, Caregiver and Sibling

Coping... Ugh, how do you cope with the unimaginable? A parent's (and/or caregivers) worst fear? The short answer is that you cope because you will have no other option but to cope, you do the best you can for your child. Sometimes you cope well, and other times not so well. Give yourself permission to know you will take a few missteps along the way. Use your support team to keep you going and ask them to remind you to take a break. Again, self-care will keep you strong and better able to cope.

What is good for you is best for your child as well. The better you cope, the better it is for your child and family.

Try various methods and determine what works for you. You are faced with so many difficulties: fear and uncertainty, work and finances, isolation (sometimes only emotional but other times both emotional and physical as treatment takes you far from home), change in relationships and trying to emotionally and physically support your cancer child along with siblings, spouse and rest of family. The list of obstacles you face in taking care of your child is daunting but you can do this.

You are in an unimaginable situation. Accept that others will only understand what you share with them. If it is unimaginable to you and you are living it you will need to remember that those around you have less understanding than you do as they are not living it! Learning to share may be something you need to do and will make life easier.

Take each moment as it comes. As treatment evolves, your life and plans have to evolve too. This can be extremely hard for people that are planners by nature. The reality of treatment is hard. You will not be able to plan far into the future so try to let this go. Having tentative plans is great! Having plans set in stone likely will not work well, and can set you up for additional disappointment.

Some Ways To Cope:

- Exercise, yoga or meditation for stress relief and focus
- Medication (anxiety, insomnia, and depression are very common, talk to your doctor as medication can sometimes help you cope and be the best parent possible during this time)
- Talking with friends and family
- Talking with another parent or patient who has dealt with osteosarcoma (MIB Ambassador Agents can pair you with someone- see www.MIBAgents.org)
- Finding joy and fun things to do when possible - even a walk on a beautiful day can help remind you of the joy in life. Movies, making cookies, art projects, seeing a theater performance, eating dessert for dinner, going to the zoo, play date, etc.
- Therapy or counseling (often it is needed as a family and as an individual)

Coping with the reality of your child having cancer is very challenging. But you need to be emotionally and physically present to help him or her. Keeping yourself healthy, rested and in a positive frame of mind is essential so that you can be your best. Cancer can teach you to enjoy every moment and not take minor daily things for granted, use that hard-learned wisdom to live every moment to its fullest.

Balancing Work and Treatments

Osteosarcoma treatment is all consuming, but many families (and/or caregivers) have financial and insurance obligations that require they work. Discussing options with the social worker at the hospital, your boss, human resources, etc. can often help in determining what options exist for you and your spouse. This is another example of how learning to share information, that you might normally consider personal or private can help. Your boss and co-workers will only understand the demands placed on you if you share your experience with them. For your own health and relationships, having balanced conversations is also necessary. Share your cancer fight when appropriate, but also be sure to continue to have conversations that don't revolve around cancer. With understanding comes compassion. Discussion of how to use vacation time, FMLA (family medical leave act), non-paid leave, etc. will allow you to understand your options. Relying on family and close friends can help alleviate the demands of treatment allowing you to work. Someone, other than you, may be able to spend time with your patient or take him/her to appointments while you go to work. Someone can sit with your child, so you can go to his/her sibling's ball game or celebrate some special occasion with them. Balance is difficult but important.

At the hospital, you will see parents taking conference calls and doing work in their child's room or in the family lounge. I've seen many grandparents swap time with the parents so that work or care of siblings can be shared. It can be a puzzle of moving pieces that changes throughout treatment but balancing it all, as imperfect as it may be, can and will happen. Reach out, ask for help and you will manage a way forward. Do not be embarrassed or ashamed that you may need to work, many do. And work is important not only as a source of income or insurance, but to help us remain who we are. In some situations, it is good for our patient to see us working. Work is normal and normal can be reassuring that things will get back to normal.

Changes in Relationships

A common quote is, “Hard times reveal true friends.” Unfortunately, many people find that some of the people they expect would be there in tough times, are strangely absent. That can be terribly disappointing but does not necessarily negate them as being a friend. Remember you had no understanding of what life with osteo was like before your patient was diagnosed, your family and friends don’t either. Some people will be absent because they don’t understand and not necessarily because they don’t care. Some people will disappoint us not because they intended to, but because despite their best efforts they fell short of what we needed or expected. People doing their best are doing their best. We can avoid becoming bitter if we accept what is and enjoy what is offered instead of focusing on what is absent.

The other side of the coin is you will likely find there are unexpected people who show up that you didn’t foresee! Also, you will meet people walking a similar journey in the hospital, Ronald McDonald house, clinic, social media, travel or on support groups. Celebrate these new people in your life! Surround yourself with people that are positive, helpful and true, they will lift you up and keep you going.

Relapse

Relapse is when the disease is detected after previously being N.E.D or N.E.R.D. Understandably this can be a heartbreak time, you might even be angry. This is a time to pay attention to your feelings. Take time to think and feel. Your medical team will present you with treatment options. You must gather your support team to help fight another battle. It is important that you do not fight this alone. Know that many patients have relapsed and end up being long-term survivors. Don’t give up hope. Be positive, no one wants to relapse or gear up for the fight again, but when you need to, you will. That is living the love you have for your warrior.

How your Support Team Can Help

Often our personal team, families, and friends, feel so terribly powerless and want to do anything to help. Some ways they may be able to help are...

- Organize a blood or platelet drive (receiving blood products is usually necessary at some point during treatment)
- Organizing a meal train for the family (be sure to give guidance

about restrictions based on tastes or items not allowed when neutropenic)

- Giving gift cards for meals, gas or household supplies
- Taking siblings on a special day
- Sit with the child while caregiver has time for self-healing through a massage or some other favorite activity or can go to work or spend time with another family member
- Small gifts from an Amazon registry
- Lawn care or house cleaning
- Pet care
- Contributing to osteosarcoma-specific research in your patient's name

Future Treatment Options

Traditionally osteosarcoma is all treated the same. This is still the case, but new research is considering options to treat each case differently based upon the genetic makeup of the individual tumor. Research shows that osteosarcoma tumors are highly variable. While the cancerous cells are all osteosarcoma, the genetic mutations creating these cells often vary greatly between patients. Future therapies are considering using a patient's tumor genetics to utilize a specific regimen based upon the tumor growth mechanisms specific to that patient's tumor. This is where having your child's tumor genetically tested would be helpful.

See clinical trial resources in the appendix.

Thoughts From Those That Have Been There – “I Wish I Knew”

Patient Perspective:

Amanda from New Jersey says, “Know there are many who have survived relapse... right away and years after. Never give up hope.”

Amanda from New Jersey also adds, “To call yourself a “Survivor” is wonderful. It’s a gift. Treat it as such. Live every day to its fullest, give back and remember those we have lost and keep them alive through your words and your prayers. Live as healthy as you can and go for your follow-ups. Life will now be filled with more worry than you ever imagined possible, but how lucky are you that you are able to worry? “Survivor’s Guilt” is something that can weigh very heavily on you... but try not to let it. Know that you can either treat your cancer as a curse or a gift. Make it a gift.”

Family Perspective:

Dad from CA says, “Balancing work and our son’s treatment created challenges, but I was fortunate to have a very supportive boss and team of co-workers. I offered to take a family care leave, knowing I needed to spend a significant amount of time at the hospital during treatments. My boss and company said no. They allowed me to come into the office when I could and work from the hospital or home as needed. My boss and co-workers found ways to redistribute work so that they picked up things requiring presence in the office while leaving things for me that could be done remotely or at random hours of the day or night. The lesson I learned was everyone wanted to find a way to help. Discuss your needs with your boss and you might be surprised what they are willing to arrange.”

Celia, a mom from Long Island shares: “As my son recovers, he says we talk about cancer way too much in our family. Instead of a Swear Jar, my survivor made a ‘Cancer Talk Jar’. Every time someone talks about cancer in front of him, they have to put a dollar in the Cancer Talk jar. I owe thousands of dollars!”

Maureen, Mom from New York says, “I wish I knew a way to guide you to a world post-recovery where you are confident that you did the best you could, with the information you had, in very difficult circumstances.

Confidence can bring you peace. None of us are prepared for this - not the patients, not the parents, not the siblings, not the people around us who love the patients. Every day we will be forced to make decisions... big ones like what type of surgery to have and little ones like should you punish your child for being fresh or should you change the channel because the patient wants to see something the family is not currently watching. We are called to make them and we must move forward into recovery knowing we made each decision the best we could with love in our heart every step of the way. So, what can I offer you that will guide you to reach a place of confidence?

Trust yourself. Trust your child. When all else fails, take a moment to listen to yourself and your child.

Communicate. Talk. Listen. Not only to the doctors but to your child. To your children. To your spouse. To your best friend who may see things you miss.

Celebrate the small things and the good days.

Create wonderful memories through the darkest of times.

Advocate. Don't be afraid to let the world know what your child needs. Politely, kindly 'fight' for your child so their place in the world is preserved. Advocate for your child with the medical team and with the school to get your child what s/he needs. Figure out what is important to your patient. If Halloween is a big deal, advocate being home for Halloween if at all possible. If going on a class trip is super important to your patient, advocate for that to happen seeking creative planning so your child can participate.

Always say thank you. Even when it is after a hard-fought battle - say thank you with your teeth gritted if need be but acknowledge how someone helped you. You will enjoy the memory of the victory better if it ends with a graceful thank you.

Let your love be active - hug, touch, cook, laugh,
if you think it, feel it - do it!"

APPENDIX



Included In This Section:

Resources

Glossary and Acronyms

Resources

MIB Agents FACTOR Osteosarcoma Conference:

FACTOR stands for:

Funding * Awareness * Collaboration * Trials * Osteosarcoma Research

The annual MIB FACTOR conference brings together the top researchers, physicians, and surgeons in osteosarcoma to share and collaborate on the latest research, advances and techniques along with patient families. The conference includes an OsteoWarriors HQ for osteosarcoma patients, survivors, siblings and OsteoAngel siblings for fun and friendship. See MIB Agents website for more information (www.mibagents.org)

Mobilizing Your Support Group:

- **Facebook** page for journey information
- **MIB Agents website** for resources, support, and for conference information (www.MIBagents.org)
- **PostHope** page (www.posthope.org)
- **CaringBridge** page for journey info for family/friends, blogging along with being able to look back at your journey from a historical perspective and potential for fundraising (www.caringbridge.org)
- **MIB Agents Family Funds** Family Funds are an important part of Making It Better for OsteoWarriors everywhere. These children and families are committed to raising funds in honor of their OsteoWarrior to Make It Better for others.
(www.MIBagents.org/Family-Funds)

Information:

- **Amputee Coalition** is the leading, national nonprofit organization working to support people living with limb loss and limb difference, their families and healthcare providers. The Coalition's mission is to reach out to and empower people affected by limb loss to achieve their full potential through education, support, and advocacy, and to promote limb loss prevention. (www.amputee-coalition.org)
- **Osteosarcoma Information Hotline** a free of cost service of the Osteosarcoma Institute. The Osteosarcoma Information Hotline provides general guidance about the treatment of osteosarcoma. This Hotline resource will help patients, their families and physicians. Providing referrals for care if you wish. Medical care or specific medical advice is not provided. (<https://osteosarcoma.info/>)
- **Texas Children's Hospital** has an amazing list of information and resources in a publication called "Beyond Diagnosis": (<https://www.texaschildrens.org/departments/cancer-and-hematology-centers>)
- **Smart Patients** MIB Agents Osteosarcoma message board (www.smartpatients.com)
- **Healios®** is a dietary supplement that many OsteoWarriors have found to minimize mouth sores from chemotherapy (www.enlivity.com/healios/)
- **Sarcoma Alliance** www.sarcomaalliance.org
- Facebook Groups- Remember that any post or response made on a public group can be seen by any of your friends. If the information is sensitive or you have a child that does not want information public then consider a closed or secret group where posts and responses can only be seen by members of the group.
 - Osteosarcoma (Bone Cancer) Survivors, Family and Friends (PUBLIC)
 - Sarcoma Support Initiative (CLOSED)
 - Sarcoma Alliance (PUBLIC)
 - Momcology (CLOSED)
Only parents of childhood cancer fighters can join
Subgroups for sarcoma are part of the site

- Rotationplasty (CLOSED)
- Amputee Help and Support Line (CLOSED)
- Bone Cancer Support... for lives touched by Osteosarcoma & Ewing Sarcoma (CLOSED)
- **Liddy Shriver Sarcoma Initiative** (www.sarcomahelp.org) has a list of sarcoma centers and specialists
- **Sarcoma Foundation of America** (SFA) www.curesarcoma.org

Clinical Trials:

- A database provided by the **U.S. National Library of Medicine** lists all publicly and privately supported clinical studies of human participants around the world. www.clinicaltrials.gov
- **Smart Patients** also has a clinical trials page that many find easy to navigate. www.smartpatients.com

Finances:

- **CaringBridge** page
- **GoFundMe**
- Selling shirts, rubber bracelets, charity runs or tournaments
- **Suzanne Renee Leider Memorial Assistance Fund** helps patients get a second opinion www.sarcomaalliance.org
- There are many national and local organizations that also can help with finances in certain situations. Your social worker is likely a good place to ask/look for options.
- You can try Googling ‘resources for families dealing with pediatric cancer in your community’
- MIB Agents Resources page (<https://mibagents.org/resources-3/>)

Glossary And Acronyms

Studies:

EURAMOS: EURAMOS stands for European and American Osteosarcoma Studies. It is a group formed to leverage international collaboration to help study and develop improved treatments for osteosarcoma.

EURAMOS-1: EURAMOS-1 was the first trial taken on by the EURAMOS body founded in 2001. It is a randomized study to see if the addition of IE to MAP in the treatment of those with poor response to initial chemo improved outcomes. It also was a

randomized study to see if the addition of interferon-a to those with good response to initial treatment improved outcomes.

Chemotherapies and Surgery:

LSS: LSS is a shorthand for Limb-Salvage or Limb-Sparing Surgery. It is a complex surgery that removes the entire tumor along with the surrounding bone. If the tumor extends out of the bone then the bone along with the muscle and tissue the tumor touches are all removed. The bone is typically replaced with a bone graft or an internal prosthesis to preserve the majority of functionality.

MAP: MAP is a shorthand representation for the three chemotherapies most commonly used in the treatment of osteosarcoma; M=Methotrexate, A=Doxorubicin (Adriamycin) and C=Cisplatin (also called Platinol®).

MAPIE: MAPIE is a shorthand representation for the five chemotherapies commonly used in the treatment of osteosarcoma when a poor response is seen post-surgery; M=Methotrexate, A=Doxorubicin (Adriamycin), C=Cisplatin, I=Ifosfamide, and E=Etoposide.

MTX: MTX is a shorthand representation for Methotrexate, chemotherapy used in the treatment of osteosarcoma. (the “M” in MAP or MAPIE).

HDMTX: HDMTX is a shorthand representation for High-Dose Methotrexate, the high-dose is often used in the treatment of osteosarcoma if tolerated.

Blood Tests:

ANC: ANC stands for Absolute Neutrophil Count. Neutrophils are a type of white blood cell that helps fight infection. ANC is part of the report from a CBC (complete blood count) test. If the ANC is too low a condition called Neutropenia exists and doctors will recommend special instructions to minimize the risk of infection while the body is in this state of low tolerance to infections.

CBC: CBC stands for Complete Blood Count and is a type of test doctors request on a patient’s blood. It provides information about

the type, count and concentration of the blood's makeup.

Hct: Hct stands for Hematocrit. Hct is the percentage of red blood cells in the blood. If this number is too low the body's ability to move oxygen from the lungs to other parts of the body may be impacted.

Hgb: Hgb stands for Hemoglobin. Hgb is the part of red blood cells that carry oxygen from the lungs to other parts of the body and brings carbon dioxide back to the lungs.

Plts: Plts stands for Platelets. Platelets are the part of the blood associated with promoting clotting or clumping to stop bleeding when the body is injured. Treatments for osteosarcoma can lower the body's platelet count. If the count drops too low, doctors may recommend a transfusion.

RBC: RBC stands for Red Blood Cells. RBC's are also called erythrocytes and are the part of the blood associated with carrying oxygen throughout the body in the hemoglobin contained in the RBCs. It is typically part of the CBC Blood test ordered by doctors.

WBC: WBC stands for White Blood Cells. WBC's are also called leukocytes and are the part of the blood associated with fighting infection. During osteosarcoma treatments, the number is reported from blood tests to determine the impact of chemotherapy on the body's ability to fight infections.

Lines and Ports:

IV: IV is short for intravenous and refers to the apparatus used to deliver drugs or fluids directly into the bloodstream via a vein. IV is also used to refer specifically to the needle and tubing inserted in the arm to deliver drugs or fluid. Other devices used to provide IV therapy are PICC lines and Port-a-Caths.

PICC: PICC is short for Peripherally Inserted Central Catheter. A PICC line is a catheter surgically inserted in a central vein, typically in an arm. While it is installed under the skin, a portion of the catheter, "tail", sticks out of the skin. The PICC line requires special care to keep it clean and sterile. The benefit of having a PICC line is

reducing the stress and damage that repeated placement of IV's can cause on the veins.

Port: Port is short for Port-a-Cath which is an intravenous catheter device that is placed under the skin and used to give treatments like fluids, drugs, and blood product transfusions. It is also used to draw blood for tests. The Port is typically placed in the chest. The benefit of having a Port is reducing the stress and damage that repeated placement of IV's can cause on the veins. It is also less susceptible to infections than other approaches. It appears as a bump in the skin and often compared to what a pacemaker looks like. For some chemotherapies, a port is required for the safety of the patient.

De-Port: De-Port is a humorous term used by many patients and their caregivers to refer to the time and procedure to remove the Port-a-Cath once treatments are complete and it is no longer needed. Similar to the celebration of the "end of chemo", the removal of the port is a milestone to celebrate. Often a "Port Party" or "Deportation Party" ensues.

Scans and Tests:

Bone Scan: Bone Scans use nuclear imaging to create a full body image of the skeletal structure and any differences in bone metabolism. The process involves an injection of the tracer and requiring a couple hours for it to be absorbed into the bone. Then the imaging is taken in a process that requires the patient to lie still on a table for about 30 or more minutes while the scanning equipment moves across the body. For osteosarcoma, bone scans are used to isolate the area of the tumor and determine if it has metastasized to any other bones in the body. In addition, it is used during follow up scans to see if any recurrence has occurred.

CT: CT or CAT scan is short for Computed Tomography and is an imaging tool used for diagnostics. It's a computer-guided combination of many x-rays taking cross-sectional images to create a three-dimensional image of organs, bones and soft tissue. For osteosarcoma chest CT's are frequently used to see if it has metastasized to the lungs. A CT can be easily visualized by thinking about slicing into a loaf of raisin bread. Some 'slices' yield a raisin and some don't. In a CT scan takes photos of slices capturing a possible tumor is

analogous to slicing bread and ‘catching’ a raisin.

MRI: MRI stands for Magnetic Resonance Imaging. It is a medical imaging approach used to obtain pictures of organs and soft tissue in the body. It uses a magnetic field instead of radiation like X-rays and CT scans. For osteosarcoma, MRI's are used in the initial diagnosis and as a pre-operative tool to determine the size and location of the tumor.

PET: PET is short for Positron Emission Tomography and is a scan that uses a tracer or die to create imaging that allows doctors to see how tissues and organs are functioning. PET scans are routinely used in the diagnosis and treatment of other cancers. In osteosarcoma, doctors may use a PET-CT but are often referred to just as a PET scan. The combination of PET and CT allows doctors to see better abnormal activity associated with cancer along with details on location and size. Many osteosarcoma patients never have a PET scan as there is some debate of the usefulness of the data and false readings.

Status:

N.E.D.: NED stands for No Evidence of Disease. Generally, a patient is considered NED from their end of therapy clear scans to 5 years post-treatment after which they are considered a survivor.

N.E.R.D.: NERD stands for No Evidence of Recurrent Disease. Generally, a patient is considered NERD from their end of relapse therapy clear scans to 5 years post-relapse treatment after which they are considered a survivor.

Thank You from the Author

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Maureen Smart, LCSW-R, ACSW, MIB Agents Ambassador Peer Training Chief, and OsteoMom for offering clinical consultation and editing to the multiple drafts along the way. Her commitment to Making It Better is always inspired by her daughters: Meghan, Mj, and Maeve (OsteoSurvivor).

Briana Paronto, MIB Agents Marketing and Donor Relations Chief, her artistry made this manual pleasing to the eye in a way we could not have without her.

Amy Woodcheke- PA, NP who helped us organize the plan for this book.

Annika Vallejo, sister to OsteoWarrior Ian for editing the second edition.

Casey Crossan, MIB Agents Development and Operations Chief, and OsteoMom to Conner for reading and guiding our work.

Linda Kennington- OsteoMom to Ryan for reading and guiding our work.

Karen Marsh- OsteoMom to Victoria who helped us organize the plan for this book.

Elyse DeNeige- For illustrating the cover of the book.

Joyce and Bernard Zimmerman Foundation- For their generous support in printing this book.

Thank you to all the OsteoWarriors and OsteoFamilies who offered their thoughts and shared their experiences in their osteosarcoma diagnosis, treatment, and recovery.

MIB Agents
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This book is available as a free digital download in English, International Spanish and Chinese at www.MIBagents.org

OSTEOSARCOMA: FROM OUR FAMILIES TO YOURS

Second Edition

Support for OsteoFamilies By OsteoFamilies

An osteosarcoma (OS) diagnosis is usually shocking, leaving you frightened and full of questions. This book hopes to bring you knowledge of; the disease, its treatments and the experiences of our community of Osteosarcoma families. The details of our journeys may be different, but there is a unique connection to others that have walked the osteosarcoma path that is strong and comforting. Together as a community, we will Make It Better for people with osteosarcoma.

**MIB Agents is grateful to the
Joyce and Bernard Zimmerman Foundation
for their generous support in printing this book.**

About The Author



Elizabeth Vallejo is MIB Agents Program Chief. Prior to osteosarcoma entering the Vallejo Family's life, she was a science teacher and school administrator from Chicago. She has been traveling with her husband Eric and twins, Ian and Annika, around the world for twelve years as they worked in International Schools. Their osteosarcoma journey started in May 2015 when her son, Ian, was diagnosed with osteosarcoma in his tibia. Ian battled for three years through two relapses with tumors in his sacrum, and lungs. Finally, Ian battled treatment-induced AML (leukemia). Initially, the Vallejo journey was lonely and they felt isolated. Once they found others in the osteosarcoma community it was made so much better. Liz works to help Make It Better for all in the greater Osteosarcoma family.