Navigating the Healthcare System

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• Become empowered
• Educate yourself
• Select a treatment team
• Dealing with insurance companies
• Working with your treatment team
• Staying Safe
• Resources
Becoming Empowered
Becoming Empowered

• Take ownership of your treatment
• Don’t be a “good patient”
• Stand up for yourself if things don’t seem right
• Be willing to make your doctor uncomfortable
• Ask questions until you understand
• Prepare for your doctor visits
Educating Yourself
Learn the Specifics of your Chordoma

• Location
• Tumor size
• Has it metastasized?
Location

- Clival
- Cervical
- Thoracic
- Lumbar
- Sacral
Sacral Location & Level
The Internet

• Decide what you are looking for (treatments, support groups, clinical trials, etc)
• If searching raises your anxiety take a break
• Choose sites carefully
  – Are they reputable? (There is a lot of misinformation on the internet)
  – Paid links
Chordoma Treatment Info | UPMC.com
www.UPMC.com/BrainSurgery

Treatment - Chordoma Foundation
www.chordomafoundation.org/treatment
What you need to know about getting treatment for chordoma.

Chordoma: Diagnosis and Treatment Options at Mayo Clinic
www.mayoclinic.org/chordoma
Chordoma: Learn about diagnosis and treatment of chordoma at Mayo Clinic.

Chordoma Treatment & Management - Diseases & Conditions - emedicine.medscape.com/article/250902-treatment
Dec 12, 2011 - A multicenter phase II clinical trial has confirmed the clinical efficacy of imatinib mesylate in the treatment of chordoma. [10] Treatment with imatinib ...

Chordoma Treatments in Alternative Medicine
chordoma-options.com
Hundreds of users rely upon these ratings daily to help them identify reliable alternative treatment ...

Chordoma Surgery and Treatment Options | Diagnosis and...
• Is the information you are finding appropriate for the location of your chordoma?
Reputable Sites

• Chordoma Foundation: [http://www.chordomafoundation.org]
PubMed (search medical journals):
Chordoma is a rare tumor that usually occurs in the spine and base of the skull. It is a malignant tumor that grows fairly slowly. It can spread to other organs, usually the lungs. It represents only about 1 percent of all malignant bone tumors.

Description

Chordomas develop in a structure called the notochord. The notochord forms the early spine in the beginning stages of fetal development. Most of the notochord is replaced by the spine during the first six months of development. Small areas can remain, and chordomas can form in these areas.

Most chordomas occur at the base of the spine (sacrum), in the tailbone (coccyx) or at the base of the skull (40 percent), but they can occur other places in the spine.

Most patients with chordomas are between 40 and 70 years of age. Occasionally this tumor can occur in younger patients, even children. The average age of people affected is about 55 years.

Chordomas are life-threatening. They can cause death by direct growth or by spreading to other organs. They spread to the lungs about 20 to 30 percent of the time.
Treatment Centers

• Stephan Harris Center for Chordoma Care:
  http://www2.massgeneral.org/chordoma/harriscenter.htm

• Memorial Sloan Kettering:
• Johns Hopkins:  
http://www.hopkinsmedicine.org/neurology_neurosurgery/specialty_areas/spine/conditions/chordoma.html

• Mayo Clinic:  
http://www.mayoclinic.org/chordoma/

• MD Anderson: http://www.mdanderson.org/

• Loma Linda:  
http://www.protons.com/protons/index.page

• UPMC: http://brainsurgery.upmc.com/conditions-and-treatments/chordoma.aspx
For Newly Diagnosed Patients

Hearing that you have, or may have, chordoma can be an overwhelming experience. You are confronted with a flood of new information, questions and issues to deal with. We know what it's like, and we're here to help. This page provides a starting point for finding the information and resources you need to successfully navigate your new diagnosis.

1. Learn about chordoma

Knowledge is power when it comes to dealing with chordoma. These pages contain the basic information you need to know about the disease.

   - Overview of chordoma
   - Frequently Asked Questions

2. Plan your treatment

The treatment plan that you choose, especially for your first treatment, can have a major impact on your outcome. It is therefore very important to evaluate your options carefully. These pages will help you make informed decisions about your course of treatment.
Clinical Trials

- Clinical Trials: http://www.clinicaltrials.gov/
• Chordoma Foundation: http://www.chordomafoundation.org/clinical-trials/
Selecting a Treatment Team
When You First Receive a Diagnosis

• In most cases you have time to explore options
• Exception: Compression of vital structures
• Unless you live near an academic medical center will most likely will be referred to a local specialist
  – This may be a problem
During Doctor’s Visit

• Bring written questions
• Bring a notebook, take notes
• Bring an advocate
  – Friend or family member
  – Healthcare professional
Important Questions

• Are you familiar with chordoma?
• **How many chordoma patients have you treated?**
• What were the outcomes?
  – Recurrence rate
• What were the complications?
Multiple Opinions

- Always a good idea
- Don’t see a doctor in the same practice
- Don’t see a good friend of the first doctor
- Get an opinion from an expert
How Do You Find Experts?

- Pub Med – Search for papers on chordoma & see who the authors are then check hospital web site
When Seeking a Second Opinion

• Facility may request records & imaging before visit.
• May require travel
• Explain what first doctor suggested and ask what this doctor thinks about it
If the Second Doctor Agrees with the First

• Who do you like more?
  – Training & experience
  – Results
  – Bedside manner
  – Support services

• Who is more convenient?
  – Closer to home
  – Insurance issues
If Second Doctor Disagrees with the First

• Change doctors
  – May require travel

• Consider a 3d opinion

• Stick with the original doctor
  – Ask what he thinks about the 2\textsuperscript{nd} doctors opinion
Dealing With Insurance Companies
Some Facts

• Chordoma is expensive to treat
• Insurance companies make money by NOT paying for your healthcare
• Your insurance company has a large bureaucracy dedicated to the prior authorization process
• Insurance companies outsource parts of the approval process to third parties
• Chordoma is rare & until recently there were few treatment guidelines
• You will probably know more about chordoma than the healthcare professionals you will speak with at your insurer
Pre-Approval Process

• Provider files request for service
• Reviewed by clerical personnel
  – Works strictly off of algorithms
• Reviewed by nurse (RN or LPN)
  – Still working off of set of standards may be able to approve tests
• Reviewed by MD
  – Initial rejection common
• Peer to Peer
• If rejected have to follow insurance company appeals process
National Comprehensive Cancer Care Network (NCCN) Guidelines

• Group of 21 US Cancer Centers
• Create evidenced based guidelines for care
• Insurance companies look at these guidelines when deciding if they will approve care
• Until February 2013 they didn’t cover chordoma
• Version 2.2013 of Bone Cancer Guidelines cover chordoma
• Document written by a committee
NCCN Guidelines

• Workup
  – Recommends full spine MRI
  – MRI of affected area
  – CT chest, abdomen, pelvis
  – CT of affected area
  – PET in certain cases
NCCN Guidelines

• Treatment
  – Surgery
  – Radiation
  – Systemic Therapy
NCCN Guidelines

• Surveillance – Every 6 months for the first 5 years, Yearly thereafter
  – Physical exam
  – MRI of site
  – Chest CT
What You Can Do

• Ask for a case manager
• Quote NCCN Guidelines
• Be persistent, fight for the care you need
• Work with your provider’s office
• If necessary threaten to go public
• Don’t give up
Working with your Treatment Team
Doctor Patient Relationship

• Important part of good patient care
  – Helps you get the best treatment
  – Facilitates the healing process
• Requires mutual understanding
  – Patients are stressed and scared
  – Doctors work hard and want to be appreciated
Understanding Your Doctor

• Becoming a doctor takes sacrifice
• Doctor are trained to maintain professional distance
• External pressures stress doctor’s empathy
• Your doctor and you have the same the same goal, the best possible outcome
Bringing Your Doctor Closer

• Help your doctor see you as a person, not just another patient
  – Find things in common
• See your doctor as a person
  – Notice & comment on his experience
  – Offer support/sympathy/praise
• Invest in the relationship
  – Empathy begets empathy
Communicating with Your Doctor

• Questions to ask:
  – Can you explain ALL of my options
  – What are the efficacy, risks, side effects of each option
  – How will each treatment option affect my quality of life
Communicating with Your Doctor

• Say what is on your mind
  – Pain
  – New symptoms
  – Side effects

• Be sure to get your test results
  – Don’t assume no news is good news
Communicating with Your Doctor

• Get organized
  – Get copies of everything
    • Imaging reports
    • Operative reports
    • Discharge summaries
  – Make a notebook
    • Section for questions
    • Section for your notes
What if Your Doctor is Difficult

• Try to figure out why?
  – Ego
    • Would feeding the ego get you what you want?
  – Feeling challenged
    • Try to negotiate and see his point of view
When Your Doctor is Difficult

• When you know more than you doctor
  – Be sensitive to his ego
    • “I am sure you already know this”

• When the doctor isn't engaged
  – Do you need him?
    • Expert
  – Does is lack of engagement matter?
    • Yes- dump him
    • No –Let it go
Staying Safe
In the ER

• Don’t be afraid to ask questions
• Make no assumptions
  – They must know I am here
  – The doctor must be working on my case
  – This must be the correct medicine
  – They must know about my allergy
In the Hospital

• Ask about every medicine before you swallow
  – Electronic med systems are just software
  – People design software
• If something doesn’t seem right speak up
• Be sure that your regular medications were ordered
• Everyone should wash their hands or use hand sanitizer before they enter your room
In the Hospital

• Make sure your doctors are communicating with each other
• Find out when rounds are
  – Surgeons round very early in the AM
  – Entire team may not round every day
Resources
Travel

• Join frequent traveler programs (airlines, hotel, rental car)
• Air travel
  – Corporate Angel Networks: http://www.corpangelo-network.org/
  – Angel Flight (West Coast): http://www.angelflight.org/
• Lifeline Pilots: http://www.lifelinepilots.org/
Lodging

• Hope Lodge: http://www.cancer.org/treatment/supportprograms/services/hopelodge/index
  – Sponsored by American Cancer Society
  – 31 locations
  – Free

• Hospitality Homes: http://www.nahhh.org/

• Hospital Facilities
Support Groups

• Chordoma Support Group: http://www.chordomasupport.org/
• Chordoma Survivors Facebook Page: https://www.facebook.com/groups/ChordomaSurvivorsPrivate/
In Summary
Gathering Information

• Use only reputable web sites
• Ask the same question of multiple doctors
• Write everything down
Find an Expert Treatment Team

• Chordoma Foundation Doctor List
• Treatment center web sites
• Search PubMed for authors
• As local doctors for recommendations
Working With Your Treatment Team

• Stick up for yourself but be gentile with egos

• If your doctor is being difficult consider
  – Stroking his ego
  – Compromising
  – Dumping
Staying Safe

• Always ask questions
• Get copies of your records & test results
• Make sure people wash or use hand sanitizer
Thank You

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