Navigating The Healthcare System Successfully:
- Become empowered
- Educate yourself
- Assemble an expert healthcare team
- Make medical decisions
- Work effectively with doctors

Becoming Empowered - Attitude
- 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
- Trust your instincts
Becoming Empowered - Behaviors
- Ask questions until you understand
- Educate yourself
- Prepare for your doctor visits
- Find an advocate
  - Personal
  - Professional

Finding an Advocate
- Personal Advocate
  - Friend/family
    - Accompany you to office visits/treatments
    - Stay with you in hospital
    - Help organize helpers
- Professional Advocate
  - Physician/nurse/social worker
    - Help understand treatment options
    - Help make medical decisions
    - Help you communicate with your doctors

Educating Yourself
- Location
- Tumor size
- Tumor spread
- Extent of invasion into surrounding tissues
Managing the internet
- Decide what you are trying to find
  - Treatments, support groups, clinical trials, national experts, managing side effects, etc
  - Don't surf randomly for hours
- Choose sites carefully
- Have someone else do it for you if possible
- If searching is increasing your anxiety -> stop

Reliable websites
- Pub Med (medical articles)
  - www.pubmed.com
- Loma Linda proton beam center
  - www.protons.com/chordoma
- Mass General proton beam center
  - http://neurosurgery.mgh.harvard.edu/ProtonBeam/
- Chordoma Foundation
  - www.chordomafoundation.org

Chordoma Foundation
- www.chordomafoundation.org
  - Chordoma general info
  - Doctor database
  - Clinical trials list (chordoma specific)
  - Tissue bank
    - Can donate tissue to further chordoma research
    - Contact SimoneSommer@ChordomaFoundation.org

Reliable Websites, cont...
- National Assn for Proton Therapy
  - www.proton-therapy.org/
- North American Skull Base Society (Board of Directors list)
  - www.nasbs.org/about/directors.cfm
- MD Anderson skull base tumor program
  - www.mdanderson.org/departments/skullbase
Consider clinical trials
- Phase I, II, III trials
- Placebo controlled trials
- Resources:
  - www.clinicaltrials.gov
  - www.centerwatch.com
  - www.cancer.gov/clinicaltrials
  - www.chordomafoundation.org/treatment/trials.aspx

Assembling An Expert Treatment Team

Identify Your Needs
- Treatment planning
- Surgical expertise
- Radiation
- Help with medical decision making
- Symptom relief

Treatment Planning
- Doc must be familiar with chordoma
- You can do this yourself
- Surgery
  - Method?
- Radiation
  - Proton beam therapy
  - Gamma knife (and others)
### Surgical Expertise
- Ideally surgeon would specialize in chordoma surgery
- At least should have a special interest in skull base/spinal surgery
- Make sure surgeon has enough experience
  - How many similar procedures they have done? **ASK!!**
  - AT LEAST 50 is ideal
- Ask about success & complication rates

### Radiation - choices to make
- **Gamma Knife**
  - Available at many centers
  - May be recommended by neurosurgeons
- **Proton Beam**
  - Available only at selected centers
  - May require time away from home
  - May be superior to gamma knife

### Medical Decision Making
- **Who can help you?**
  - Neurosurgeon/head & neck surgeon
  - Medical Oncologist
  - Primary care doctor
  - Neurologist
  - Patient advocate
  - Family & friends

### Symptom Relief
- **Primary care doctor/neurologist**
  - Depression, anxiety, pain
- **Neurosurgeon/head & neck surgeon**
  - Symptoms related to surgery
    - Incision pain, post op fever, post op discomforts (e.g. leg pain)
- **Radiation oncologist**
  - Radiation induced symptoms
    - Fatigue, rash, etc
- **Alternative practitioner**
  - Pain, nausea, fatigue, depression, anxiety
How To Find Experts
- Web sites of nearby teaching hospitals
  - Department emphasis
    - Look up neurosurgery/head & neck surgery
    - Skull base tumor center?
    - Sacral/spinal tumor center?
    - Radiation Oncology
    - Proton beam therapy?
  - Physician special interest
    - Research/publications/experience
  - Look for expertise in chordoma or skull base tumors/spine surgery (depending on your tumor site)

Finding Experts, cont.
- Call a proton beam therapy site and ask for physician referrals
  - www.proton-therapy.org (links: proton cntrs)
- Find medical articles on Chordoma
  - Pub Med (www.pubmed.com)
  - Look at authors
  - Investigate their institution’s website
  - Chordoma Foundation doctor database

Example: Dr. B., MSKCC
- “I am a neurosurgeon with an expertise in primary and metastatic tumors in the spine, as well as skull-base tumors. In my role as head of Memorial Sloan-Kettering’s multidisciplinary spine tumor team (which is a group of neurosurgeons, surgeons, radiation oncologists, neuroradiologists, neuro-oncologists, and physiatrists), I have pioneered techniques to make spine tumor surgery safer and more effective...I also participate in the National Institute of Health’s International Chordoma Study Group”

Choosing a Doctor
- Generate a list of doctors
- Google their names
- Ask other doctors about them
- Call their offices, speak to the nurse
- Consider asking for a call-back from the doctor
“Interviewing” a doctor
- Explain your situation
- State that you are trying to find the very best possible care
- Ask about interest/experience in chordoma

Finding the Words
- “Please forgive me for asking, but how many of these procedures do you think you’ve done?”
- “I am looking for someone with particular interest in and knowledge about chordoma. Who do you think would be the best doctor to see?”

Second Opinions
Everyone with a rare cancer should seek a second opinion!

Second Opinion - Don’ts
- DON’T see a doctor in the same practice
- DON’T see a good friend of the first doctor
- DON’T see a doctor without a stated interest in spinal/skull base tumors (depending on your tumor site)
Chordoma can be confused pathologically with chondrosarcoma.

Pathology second opinion Centers:
- MD Anderson Cancer Center
  www.mdanderson.org
- Armed Forces Institute of Pathology
  www.afip.org

Why Bother?
- A study at Massachusetts General Hospital found that 37% of chordomas and chondrosarcomas (referred to them) were misdiagnosed at outside institutions.

Second Opinion - Local Expert
- Check web sites of local teaching hospitals
- Call neurosurgery/head & neck surgery department directly and ask secretary
- Ask other doctors who they would see & why
- Look for a hospital with a “Tumor Board”
Second Opinions - National Experts
- Often review records before you go
- Usually multidisciplinary
- May require travel - for assistance:
  - Lifeline Pilots [www.lifelinepilots.org](http://www.lifelinepilots.org)
  - Angel Flight [www.angelflight.org](http://www.angelflight.org)
- Can get surgery by expert and follow up care by home doctor

During The Visit
- Bring written questions
- Bring a notebook and take notes (tape recorder?)
- Bring an advocate
  - Personal or professional
- Explain what your first doctor suggested and ask what this doctor thinks about it

If the second doctor agrees with the first:
- Who did you like more?
  - Training & experience
  - Bedside manner
  - Support services
- Who is more convenient?
  - Closer to home
  - Easier to reach
  - Insurance issues

If the 2nd doctor disagrees with the first - 3 choices
- Change doctors
  - May require travel for treatment
- Consider 3rd opinion
  - Be sure is as experienced as the 2nd opinion
- Stick with original doctor and plan
  - Ask original doctor what s/he thinks of 2nd opinion doc’s plan
    - e.g. If neurosurgeon suggests gamma knife, could there be a bias?
Making Decisions

- Not every treatment is right for every patient
- Consider:
  - Your values
    - Independence, comfort, longevity no matter the cost, etc
  - Risk of treatment
    - Disfigurement, disability, etc
  - Need for travel/time away from home
  - Finances

There are NO perfect decisions

- Learn
- Seek council
- Engage your intuition
- Leap
- Commit

Creating An Effective Relationship With Your Doctor

- Important component of excellent 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
- Doctors are trained to maintain professional distance
- External pressures stress doctors’ empathy
  - Insurance companies, gov’t regulations, student loans, increased patient load etc

You and your doctor want the same thing - a healthy you!

Bringing Your Doctor Closer
- Help your doctor to see you as a person, not just a patient
- Find things in common
- See your doctor as a person
- Notice and comment on his/her experience
- Offer support/sympathy/praise
- Invest in the relationship
- Empathy begets empathy

Communicating with your doctor
Stand up for yourself without implying that your doctor is deficient

Communicating with Your Doctor
- Questions to ask
  - Can you explain ALL of my options?
    - Not just the one that you recommend
  - What are the efficacy, risks, side effects of EACH option?
  - How will each treatment affect my quality of life?
  - Can you help me find a national expert?
Communicating with your doctor, cont...
- Say what is on your mind
- Uncontrolled pain?
- Medicine with too many side effects?
- Medicine too expensive?
- New symptoms?
- Be sure to get your test results
- Don’t assume ‘no news is good news’

Communicating, cont...
- Get organized
  - Get copies of everything
  - Tests/radiology reports/biopsies
  - Specialist reports
  - Hospital discharge summaries
  - Make a notebook
  - Tests/doctor notes etc
  - Have a section for questions
  - Have a 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
      - “I know you don’t want to do follow-up care for someone else’s surgery. Would it help if had the other surgeon call you to discuss his technique?”

When your doctor is difficult...
- When you know more than the Dr.
  - Be sensitive to his ego
    - “I’m sure that you already know this but, I read that some people prefer proton beam therapy to the gamma knife…”
- When the doctor isn’t engaged
  - Do you need him?
    - Expert surgeon?
  - Does his lack of engagement matter?
    - YES? Dump him  NO? let it go
Avoiding Medical Errors

Beware early July!

In the E.R.

- Make no assumptions!!
  - “They must know that I’m here”
  - “The doctor must be working on my case”
  - “This must be the correct medicine”
  - “They must know about my penicillin allergy”
  - “That doctor looks young and seems nervous, but he must know what he is doing”

In The E.R., cont...

- Be vigilant and ask questions
  - “What is that medicine for?”
  - “What did the tests show?”
  - “Are you a resident? Which year?”
  - “When will I see the attending?”
  - “What do you think is wrong with me?”
  - “What other diagnoses are you considering?”
  - Don’t be afraid to speak up!

In The Hospital

- Be sure your regular medicines get ordered (if OK with your doctors)
  - Antidepressants, stool softeners, anxiety meds
- Ask about every medicine before you swallow it
- Speak up if something doesn’t seem right
In The Hospital, cont...
- Insist that EVERYONE wash their hands before touching you or your tubes
- Find out when Rounds usually happen
- Ask for bedside Rounds if possible
- Keep someone with you as much as possible

Communication In The Hospital
- Make sure that your doctors talk to each other
- “Does doctor X know about this test? What did he say?”
- Feel free to call your doctors from your hospital bed
- When your nurse says s/he’ll call the doctor, make sure it happens - don’t assume

Summing it all up
Getting what you need from the medical system

Stay Safe - avoiding medical errors
- Get copies of your tests and READ THEM
- Help your doctors communicate with each other
- Be alert - especially in the hospital
Gather information
- Stick to well known medical websites
- Ask the same questions of multiple doctors
- Write everything down

Formulate An Expert Treatment Team
- Search teaching hospital websites
- Physician special interest/training
- Departmental emphasis
- Find authors of articles on chordoma
- Ask local neurosurgeons/head & neck surgeons/oncologists for recommendations
- Visit www.chordomafoundation.org

Work Effectively With Your Doctors
- Stick up for yourself but be gentle with your doctor’s ego
- If your doctor is being difficult, consider:
  - Stroking his ego
  - Compromising
  - Dumping him

Keeping Yourself Sane
- When your info searching begins to repeat, try to stop for awhile
- Once you’ve made a decision, commit to it
- Find doctors that you trust, and then trust them
Advocating for yourself requires contradictions

You must assertively take control... and then, when the time is right, bravely let it go

Thank You For Your Attention

Delia Chiaramonte, M.D.
Insight Medical Consultants
1014 Dulaney Valley Road
Towson, MD 21204
(443) 695-9219
www.insightmedicalconsultants.com
dc@insightmedicalconsultants.com