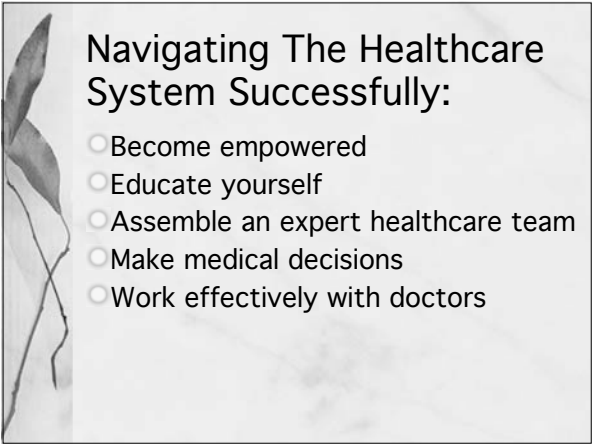


Navigating The Healthcare System When You Have A Chordoma

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Navigating The Healthcare System Successfully:

- Become empowered
- Educate yourself
- Assemble an expert healthcare team
- Make medical decisions
- Work effectively with doctors




Becoming Empowered

Attitude
Behavior




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



Learn the specifics of your illness

- 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/?orthopedic 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)

Second Opinions - Pathology

- 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

Pathology Second Opinions, cont...


- Pathology Departments of major cancer centers
 - Especially if have proton beam therapy there
 - Be sure they have specialty pathologists (NOT gen'l pathologists)
 - E.g. Mass General Department of Bone and Soft Tissue Pathology

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
 - Angel Flight 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



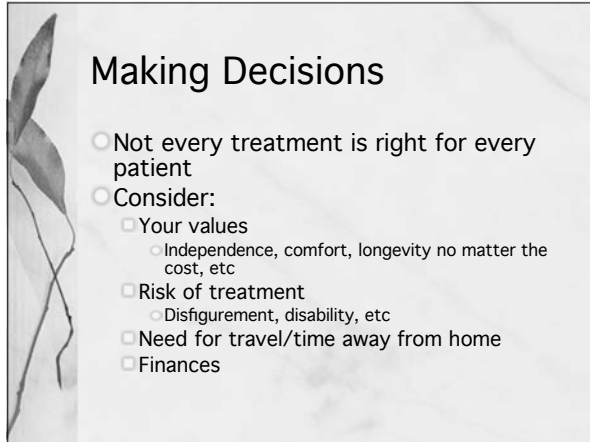
If the second doctor agrees with the first:

- 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



The Doctor-Patient Relationship


- 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



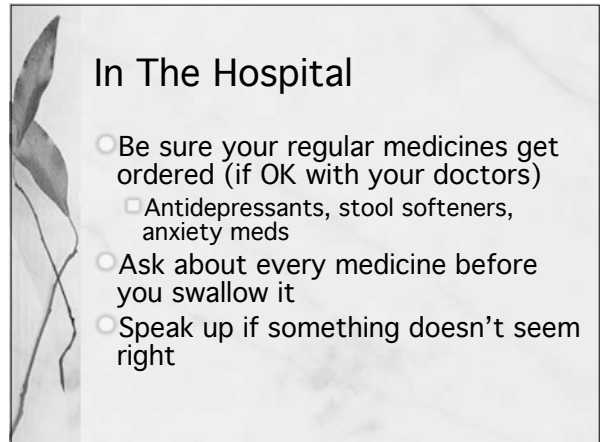
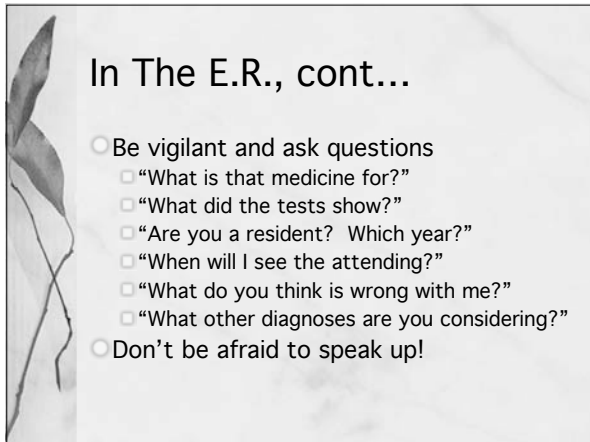
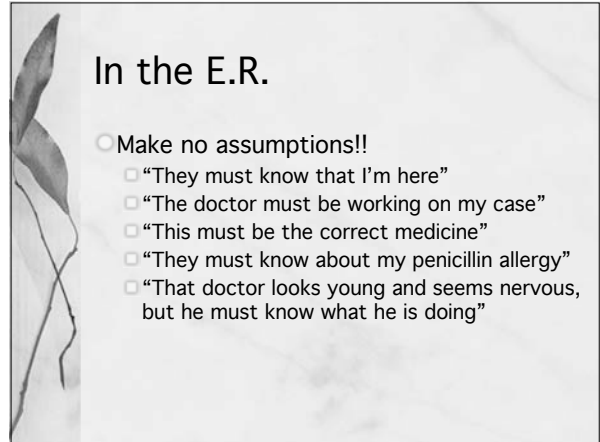
What if your doctor is difficult?


- 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






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 OR
 - Compromising OR
 - 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

