

**CHORDOMA
FOUNDATION**

You're in the drivers seat
Navigating the medical system
November 22, 2015

Navigating the medical system

1. Become empowered
2. Educate yourself
3. Assemble an expert healthcare team
4. Work effectively with doctors
5. Make medical decisions
6. Insurance
7. (Personal) Key take aways

CHORDOMA FOUNDATION 2

1. Become empowered

- I. Attitude
- II. Behavior
- III. Finding an advocate

CHORDOMA FOUNDATION 3

I. Attitude

- Don't be a good patient
- Take ownership of your treatment
- Stand up for yourself if things don't seem right
- Be willing to make your doctor uncomfortable
- Trust your instincts

CHORDOMA FOUNDATION 4

II. Behaviour

- Educate yourself
- Prepare for your doctors visit (written questions)
- Ask questions until you understand
- Get organized:
 - Take notes during all visits/calls/meeting; and/or
 - Make a report and an action plan afterwards
 - Follow up your actions on a short term
 - Ask for copies of all available medical records and read them
- Help your doctors communicate with each other
- Bring an advocate

CHORDOMA FOUNDATION 5


III. Finding an advocate

- Personal advocate
 - take care of you and your environment
 - push on attitude & behavior
- Professional advocate
 - medical decision making

CHORDOMA FOUNDATION 6


III. Finding an advocate

- Personal advocate – “take care of you and your environment”
 - What: accompany to office visits/treatments
Stay with you in hospital
Help organize helpers
 - Who: family and/or friends

 7


III. Finding an advocate

- Personal advocate – “push on attitude & behavior”
 - What: 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
Educate, prepare & get organised
 - Who: The “rational” family and/or friends, CF, other patients (not necessarily Chordoma)

 8

III. Finding an advocate

- Professional advocate – medical decision making
 - What: Help understand treatment options
Help make medical decisions
Help you communicate with your doctors
 - Who: Professionals by education: Physician/nurse/social worker
 - Who: “Professionals” by experience: Chordoma patients/caregivers, Facebook group

 9

III. Finding an advocate

- “Social” family & friends:
 - take care of you and your environment
- “Rational” family & friends
 - push on attitude & behavior
- Other Chordoma patients/CF
 - push on attitude & behavior
 - medical decision making
- Professionals by Education
 - medical decision making

CHORDOMA FOUNDATION 10

Navigating the medical system

1. Become empowered
2. Educate yourself
3. Assemble an expert healthcare team
4. Work effectively with doctors
5. Make medical decisions
6. Insurance
7. (Personal) Key take aways

CHORDOMA FOUNDATION 11

2. Educate yourself

- I. Specs of Illness
- II. Identify your needs
- III. Searching & sources

CHORDOMA FOUNDATION 12

I. Specs of Illness

- Tumor location/size/spread & possible invasion into surrounding tissues
- Possible side effects
- Statistics

CHORDOMA FOUNDATION 13

II. Identify your needs

- Your need about Treatment Planning is about:
 - Surgical expertise, or
 - Radiation, or
 - Systematic therapy, and
 - should always include a multidisciplinary approach!
- Symptom relief / palliative care
- Help with medical decision making

CHORDOMA FOUNDATION 14

III. Searching & sources

- Do not surf randomly for hours but decide what you are trying to find (your needs)
- If searching is increasing your anxiety => stop
- Have some else do it for you if possible
- Read same materials a second time and you will find new information
- Choose sites carefully, including and to start with www.chordomafoundation.org

CHORDOMA FOUNDATION 15

Navigating the medical system

1. Become empowered
2. Educate yourself
3. Assemble an expert healthcare team
4. Work effectively with doctors
5. Make medical decisions
6. Insurance
7. (Personal) Key take aways

CHORDOMA FOUNDATION 16

3. Assemble an expert healthcare team

- I. How to find an expert (long list)
- II. Choosing a doctor (short list)
- III. Selecting your doctors
- IV. Second opinions

CHORDOMA FOUNDATION 17

I. How to find an expert surgeon

- Chordoma Foundation will provide for Europe (work in progress for EU) a list of hospitals/treatment centers with:
 - Experience in Chordoma
 - Working from a multidisciplinary approach
- Websites
- Contact a proton beam center and ask for physician referrals (“backwards thinking”)
- As a result, generate a “long list” of doctors

CHORDOMA FOUNDATION 18

II. Choosing a doctor

- Do research on this long list to create your short list:
 - Google their names;
 - ask other doctors about them
 - Call their offices, speak to nurse
 - Get a referral within their network and email them
- Get in direct contact with doctors on your short List:
 - “Interview” (email/call/visit) a doctor
 - Ask the same questions to multiple doctors
 - Do your homework and formulate precise and polite: take a doctor serious in order to get a serious answer

III. Select your doctor

- Surgical expertise:
 - Make sure surgeon is experienced. Ideally specialist in Chordoma
 - Ask for statistics, success rates, complications
 - Make sure there is a multidisciplinary approach
- Radiation:
 - Proton Beam
 - Carbon Ion
- Systematic therapy
 - Officially there are no approved drugs
 - However some has been proven effective for several patients
 - New drugs in progress

IV. Second opinions - process

- Everyone with Chordoma should seek a 2nd opinion (and don't forget a 2nd opinion on pathology)
- Become empowered again: attitude & behavior
- Go back to long list/short list:
 - Add doctors outside own geography (2nd opinion by email/ phone is possible here)
 - Eliminate doctors in the same practice or a good friend of the first doctor

IV. Second opinions

- The 2nd doctors agrees with the 1st. Change to 2nd doctor if:
 - More convenient (closer to home, easier to reach, insurance)
 - Better 'fit' (intuition, experience, bedside manner, services)
- If 2nd doctor disagrees with the 1st doctor, you have 3 choices:
 - Stick with original plan doctor (but ask opinion 1st doctor about 2nd opinion)
 - Change doctors
 - Consider 3rd opinion (or more...)

CHORDOMA FOUNDATION 22

Navigating the medical system

1. Become empowered
2. Educate yourself
3. Assemble an expert healthcare team
4. Work effectively with doctors
5. Make medical decisions
6. Insurance
7. (Personal) Key take aways

CHORDOMA FOUNDATION 23

4. Work effectively with doctors

- I. Communicating with your doctor
- II. Improve treatment & avoid medical errors

CHORDOMA FOUNDATION 24

I. Communicating with your doctor

- Take a doctor serious in order to get serious feedback
- Do your homework (again: behavior)
- Formulate precise
- Formulate polite:
 - Please forgive me for asking, ...
 - If I may ask your professional opinion,..
 - As a father, I have the obligation to,..

CHORDOMA FOUNDATION 25

II. Improve treatment & avoid medical errors

- Find out when rounds usually happen
- Make sure your doctors talk to each other (“multidisciplinary approach”)
- When your nurse says (s)he will call the doctor, make sure it happens and don’t assume
- Ask about every medicine before you swallow it
- Make no assumptions at all:
 - “This must be the correct procedure”
 - “the doctor seems young and nervous, but (s)he must know what (s)he is doing”
- Keep someone with you as much as possible (‘personal advocate’) to improve and avoid

CHORDOMA FOUNDATION 26

Navigating the medical system

1. Become empowered
2. Educate yourself
3. Assemble an expert healthcare team
4. Work effectively with doctors
5. Make medical decisions
6. Insurance
7. (Personal) Key take aways

CHORDOMA FOUNDATION 27

5. Make medical decisions

- Be aware that:
 - Not every treatment is right for every patient
- Take into consideration:
 - Risk of treatment / side effects / quality of life
 - Your values (independence, comfort, longevity no matter the costs)
 - Need for travel/time away from home
 - Finances / insurances
- Remember:
 - There are NO perfect decisions
- And don't forget keeping yourself sane
 - Advocating yourself requires contradictions (you must assertively take control... and then, when the time is right, bravely let it go*)
 - Once you've made a decision, commit to it
 - Find doctors that you trust, and then trust them

CHORDOMA FOUNDATION 28

Navigating the medical system

1. Become empowered
2. Educate yourself
3. Assemble an expert healthcare team
4. Work effectively with doctors
5. Make medical decisions
6. Insurance
7. (Personal) Key take aways

CHORDOMA FOUNDATION 29


6. Insurance

- Differs from country to country, however some general lessons:
 - Do not just ask or fill in standard forms
 - Be aware of the information asymmetry having Chordoma
 - Use this positions in order to be perceived as a serious patient with a serious request
 - Call write and focus on Chordoma being a rare disease and being and exception to the systems
- Cross border coverage within EU (including Switzerland, Norway, Iceland, Liechtenstein) based on standard insurance policy.
- Sometimes there is more possible than you would think at first sight

CHORDOMA FOUNDATION 30


Navigating the medical system

1. Become empowered
2. Educate yourself
3. Assemble an expert healthcare team
4. Work effectively with doctors
5. Make medical decisions
6. Insurance
7. (Personal) Key take aways

 31

7. (Personal) Key take aways

- Rule number 1: Attitude, behavior and self education as fundament for the right treatment: *your choice!*
- Rule number 2: Finding advocates: *you are not alone!*
- Rule number 3: *do not forget rules* number 1 and rule number 2 during all steps in the ongoing process, especially on rainy days...

 32
