

Advice from PATIENTS for Newly Diagnosed - February 2016	Likes
Find the most experienced chordoma doctors	13
Bring someone with you to appointments to take notes (people become overwhelmed)	9
Educate yourself, become your own advocate	7
Get second opinions by chordoma experts	7
Have a positive attitude and have faith you will be a survivor	5
Bring your written questions to appointments, take notes, write everything down	4
Regain control, learn to fight. Then fight. Use your emotions to get you there	4
Ask for the MRI/CT/PET scans (imaging) on CD , not just the reports. You will need CDs for 2nd opinions	4
Anxiety meds as needed	4
Ask for and/or except help. Lean on a support system	3
Ensure tissue removed is properly preserved for genomic testing (as needed)	3
Connect with the Chordoma Foundation and (separate) FB Survivor Group	3
Ask for ALL copies of all records quarterly	3
Exercise, take care of yourself, walk	2
Contact your countries cancer agency	2
Ask about recovery, understand more of what to expect	2
Listen to your body: need a nap... take a nap	2

Advice from CAREGIVERS for New Caregivers - February 2016	Likes
Let people help you when they offer, but not with unsolicited medical advice	10
Keep loved ones informed but limit the information you share so they don't worry needlessly and cause you more angst (i.e. tell them about pathology reports and scans AFTER you know results).	8
Just say "thank you" when people tell you about the latest "cure" or food that you need	8
Be prepared, lists of questions, get all results and opinions on paper or cd. Keep patient informed without scaring them	7
Take time for yourself. Manicure, rest, lunch with a friend	7
Keep a journal. It can be invaluable in remembering the chronological order of your medical journey. Write down every nurse, doctor, intern, medications, etc. (Log everything!)	4
Never feel guilty. You made the best decisions you could with the resources you had at the time.	4
Join a Caregivers Support Group	4
Educate yourself as much as possible about all facets of your loved one's disease	4
Have frank and open dialogue with your loved one so that they feel that they can openly and honestly express their wishes throughout treatment and beyond	4
Representation Agreement/Power of Attorney in place so if ever needed you can ensure your loved one's wishes for care/treatment can be implemented quickly	4
Be prepared to travel to get multiple expert opinions on the best treatment	3
Listen to the experience of others then feel free to follow all, some, or none of it	3
When entrenched in the drama of this disease, remember to .count your blessings	3
Follow your own path. Listen to the experience of others then feel free to follow all, some or none of it.	2

The information and communications in the Support Groups is solely for informational purposes and they are not intended to provide medical advice. None of the founders, moderators, administrators, or other members of the groups take responsibility for any possible consequences from any treatment, procedure, exercise, dietary modification, action or application of medication which results from reading or following posts within the group. The posting of comments does not constitute the practice of medicine, and any information shared does not replace the advice of your physician or other health care provider. Before undertaking any course of treatment, the reader must seek the advice of their physician or other health care provider.