

HOSPITALIZATION TIPS FOR CHORDOMA PATIENTS AND CAREGIVERS

Created by Chordoma Surgical Patients and Caregivers

Overview: Most chordoma surgeries are typically considered major. Make every attempt possible to get a private room. If a private room isn't available, request the bed farthest from the door.

Hospitals are very noisy, especially in ICU; and there is no day and no night. Patients are often awakened very early to draw blood, to clean the room, empty the trash cans, etc. Be prepared, and sleep when you can.

Visitors: Hospitalized patients need to have a yes/no voice of who visits and for how long, if anyone, following surgery. Caregivers need to be guardians that enforce whether the post-surgery patient wants to be seen at their absolute worst (hoses in noses, drains, wounds, and feeling downright crappy, druggy, and grubby. Ask the nurse if the patient can have visitors... they're very perceptive and know best what's best. "The nurses says maybe tomorrow... but call first" is great for tool for crowd control.

Visitors should not wake up sleeping patients. Let them heal and hibernate unless they want company: a patient's role is not to wake up and put on a brave face to make visitors feel better, but often that ends up being the case.

Write down questions you and the patient may have: Doctors will visit daily, some mornings and others evenings. Have a list of written questions prepared, and then write down the answers you receive.

Consider a making a list of things to bring: There is no normalcy in ICU or healing from a major surgery. Normalcy may be as simple as bringing a few items such as some considerations below.

From the Bedroom:

Pajamas or bathrobe	Hat for bad hair days	Your own pillow	Short sleeve sweatshirt
Night mask	Underwear	Sweat pants	Slip on shoes or slippers
Reading glasses	Ear plugs		

From the Bathroom:

Q-Tips	Deodorant	Hairbrush	Nail clippers
Your toothbrush	Underwear	Sweat Pants	Slip on shoes or slippers
Night eye mask	Ear plugs	Pajamas	Soft tissues (Kleenex)

Miscellaneous:

Antibacterial wipes for the IV tree, TV remote...	Antibacterial gel (for patient table/hands)	Book or e-reader	Magazines
Notepad and pen	Favorite family photos (we tapped many to the walls of the room)	Dry Erase Board : a must if you even might be intubated	<- It can be very frustrating unable to communicate

Electronics:

iPad / tablet and charger	Cell phone and charger
Headphones or ear-buds	Extension cord for bedside phone/tablet charging

From the Kitchen (for the caregiver)

Applesauce, string cheese, etc.	Small ice chest for extended visits
Nutritional drinks like Boost or Ensure	Cookies or other comfort foods

Tips for caregivers at [this link](#). Take good care of yourself; patients can tell if you don't... and they worry