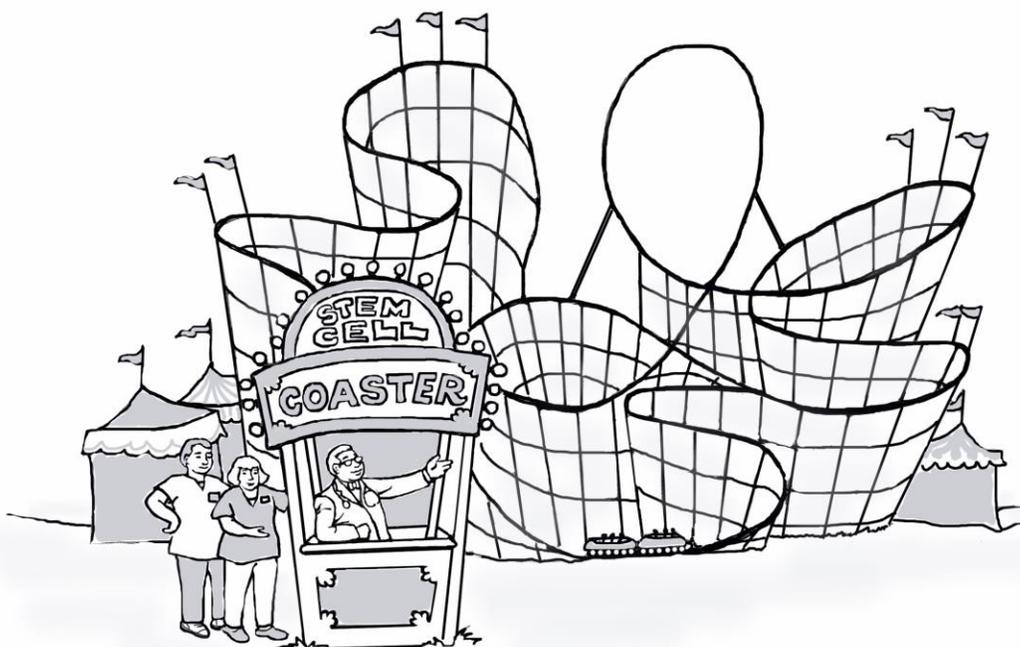
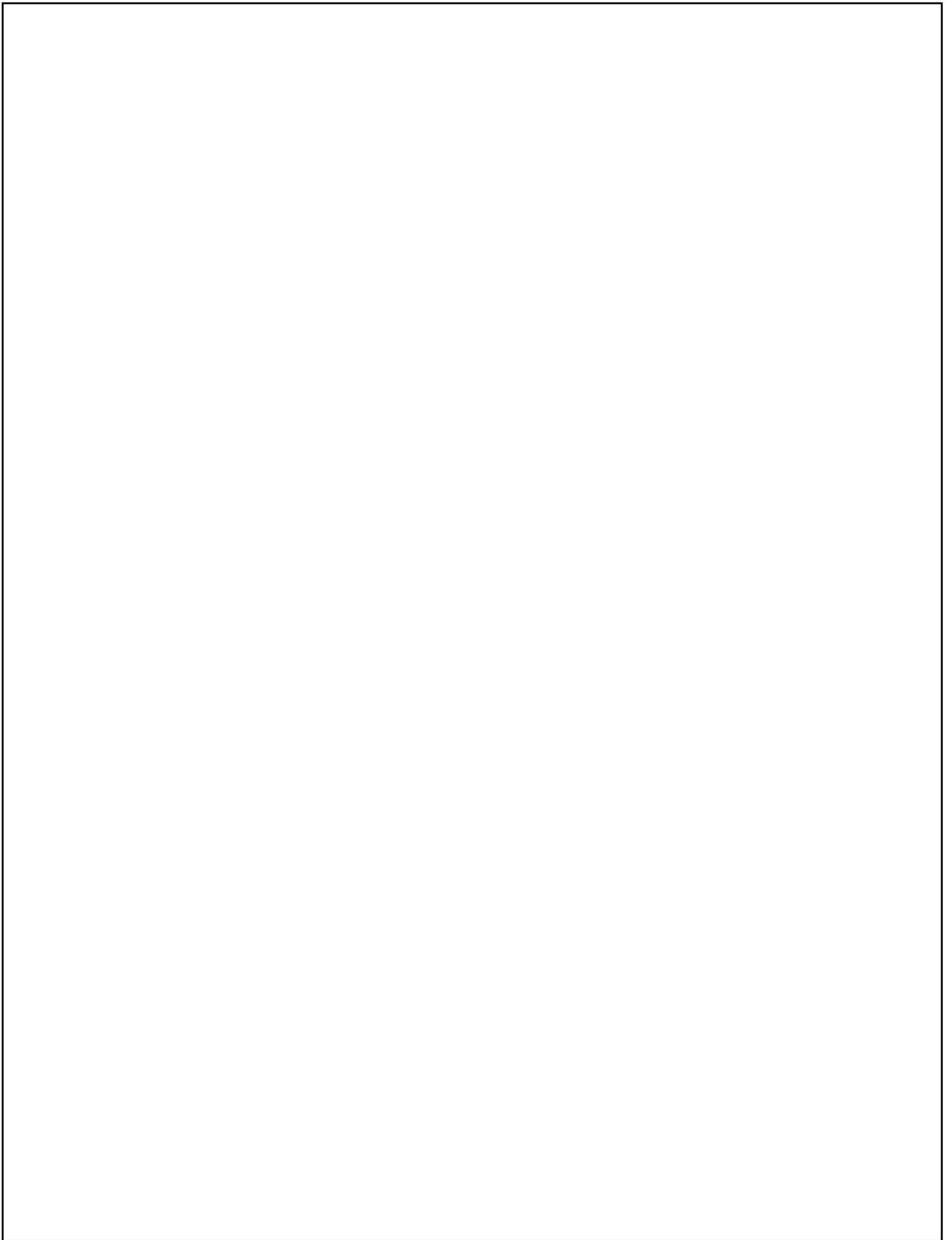


# TIPS FOR MANAGING YOUR STEM CELL THERAPY EXPERIENCE



WRITTEN AND ILLUSTRATED  
BY  
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“Life is either a Daring Adventure or Nothing at All...”

Helen Keller

## FOREWORD

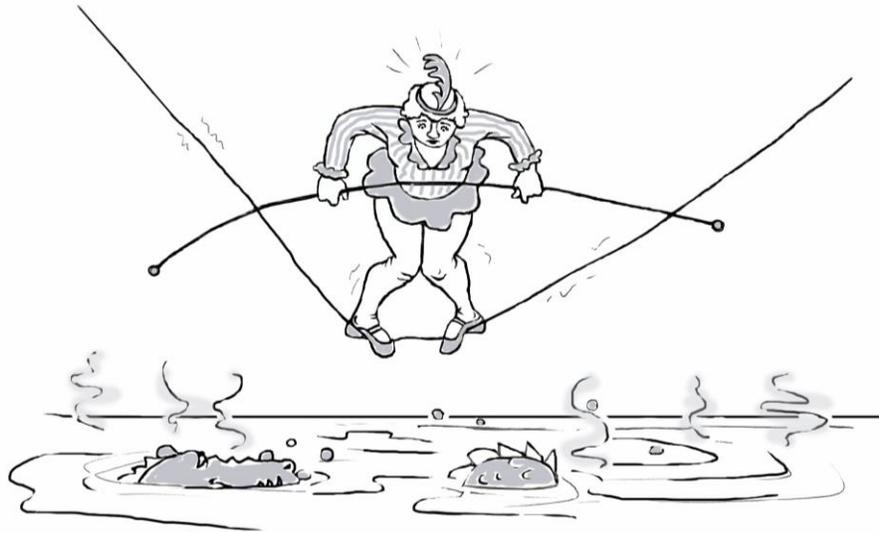
I, like you, have been dealing with cancer. I have gone through chemotherapy and radiation, and when cancer was detected again, was offered the opportunity to be treated with high dose chemotherapy and stem cell therapy. I opted for the treatment just as you have, and began the long drawn out process of qualifying for it. At last all the tests were done, and the papers were signed; I felt like I'd won a marathon and jackpot combined! Here was a chance at life, a good life.

So, all bright eyed and bushy tailed I arrived at the stem cell unit for the first step in the process. I met the nurses who would shepherd me through it all. And got a whole pile of paperwork listing all the possible side effects, what was required of me, what to expect. And the nurses were great, full of advice and anecdotes, trying to get me ready for what was coming.

But the nurses and doctors haven't experienced this process, only watched their patients go through it, and experiencing it is a whole different thing. It gives one a unique point of view, and since I have gone through it, and survived it (I know there are patients who do get much sicker than me, but we all experience the same thing, just to a greater or lesser degree) I would like to tell you how it feels, and give you some "been there" advice for this life altering journey.



**YOU NEED TO GET ALL THE NECESSARY SCANS AND TESTS  
OUT OF THE WAY BEFORE YOU ARE ABLE TO ENTER THE  
STEM CELL PROGRAM.**



## **STRESS**

What struck me forcefully quite early on in the process was how emotionally draining it was. Each test you have to go through can derail the treatment if the results are bad. You might discover you have some new disease or weakness you weren't previously aware of, at a time when you already have way too much to deal with. And you are at the mercy of your body- there's nothing you can do except keep fingers and toes crossed and hope you "pass" each test. And then there's the eternal waiting- for tests, for results, for appointments. There is nothing worse than waiting, I think: you feel so powerless.

I found it really helped to do some things that I enjoyed on a regular basis every day, to offset all the uncertainty and stress. It doesn't matter how trivial or time wasting these things might seem to other people in your life, they are your comfort zone. Long walks, soap operas, golf, jigsaw puzzles, sewing, coin collecting, biking. This is the time you really need to coddle yourself with regular stress reducers.



“Life’s Like Riding a Bicycle: To Keep Your Balance, You Must Keep Moving”

Albert Einstein

## **STRENGTH**

In addition to mental toughness it’s really important to get yourself into the best physical shape you can before taking on this treatment regimen. The period after the high dose chemotherapy is absolutely draining; one nurse told me it was “like you’ve been hit by a bus”. Well, being hit by a bus and then dragged many miles underneath it on a potholed road is more like it!

## **FINANCES**

In my case, I lived an hours' drive from the hospital where all the tests and the treatment were done, so it entailed continual driving and long days. Each test took up a whole day, really. And it's not cheap, when you factor in gas, food, babysitting. It's not cheap even when you're NOT driving, but staying in the hotel or hostel in town, because you still have to eat. Before you take this treatment on, when you are figuring out how you can manage everything, the money part should be discussed with your family and/or partner so you don't have to worry about it. I think one of the most important things to do is relieve yourself of as many worries as you can, and plan out everything ahead of time to reduce your stress as much as possible.



**LET THE STEM CELL TRANSPLANT TEAM KNOW IF YOU NEED HELP ARRANGING FOR A PLACE TO STAY DURING YOUR OUTPATIENT TREATMENTS.**



## OFF TO THE RACES



**A PICC LINE MUST BE INSERTED PRIOR TO MOBILIZATION  
CHEMOTHERAPY**

### PICC LINES

If you haven't already experienced the joys of PICC lines, here's your chance! PICC lines are wonderful and save you an awful lot of pricks with needles, but they are a real pain to live with. Trying to keep them dry when having a bath or shower is impossible with the blue plastic sleeves you will be issued. One suggestion that did work was to wrap the arm in plastic shrink wrap, but you have to be a contortionist to do it yourself - and you use up an awful lot of shrink wrap. Mine got wet regularly but it survived, so don't worry about it too much.

After battling with those elastic web things you are given to hold the PICC line arms in place, I finally got fed up and cut off the bottom of a sock and slipped what was left over the line - and EUREKA! - it worked perfectly! When I mentioned my invention to a nurse, she told me some people have complete wardrobes of cut off socks to match their outfits...wish someone had told me that at the start!



**A TEMPORARY DIALYSIS CATHETER WILL BE INSERTED ON THE FIRST DAY OF YOUR STEM CELL HARVEST PROCEDURE**

### **GETTING THE CATHETER INSTALLED**

In my hospital the darn thing was installed on one side of my neck, not my chest! If you ever wanted to look like Godzilla, here's your chance. It's big and floppy, and it's not going to go unnoticed. In the hospital some people know what it is, but they sure don't in public venues, like a hotel or restaurant.

Ladies, get yourself a nice wide scarf: it works great to cover the thing, and will hide the bandage that keeps the arms from flopping around. Men, all I can think of is a turtleneck sweater, or if you aren't embarrassed to be a fashionista, a cravat? While it's there, think positive: it's only installed for a few days.





**AFTER THE MOBILIZATION CHEMOTHERAPY YOU WILL NEED TO INJECT NEUPOGEN FOR 8 TO 10 DAYS**

**THAT NEUPOGEN INJECTION....**

The good thing about these injections is you can be at home during that week. The bad thing is you have to give yourself the injections! This is not one of those prepacked syringe systems, but a full on old fashioned syringe, and you have to know how to put the (VERY EXPENSIVE) medication into the syringe before injecting it. I was very lucky in having a husband who used to inject rats in his undergraduate days at university, so he was able to figure it out and do the shots for me; otherwise, I think I might have had to get the home care nurse to do it or go to my doctors' office or a clinic.



**YOU MUST TAKE YOUR TEMPERATURE EVERY 4 - 6 HOURS, AND STAY AWAY FROM GERMS!**



## **YOUR HOSPITAL STAY**

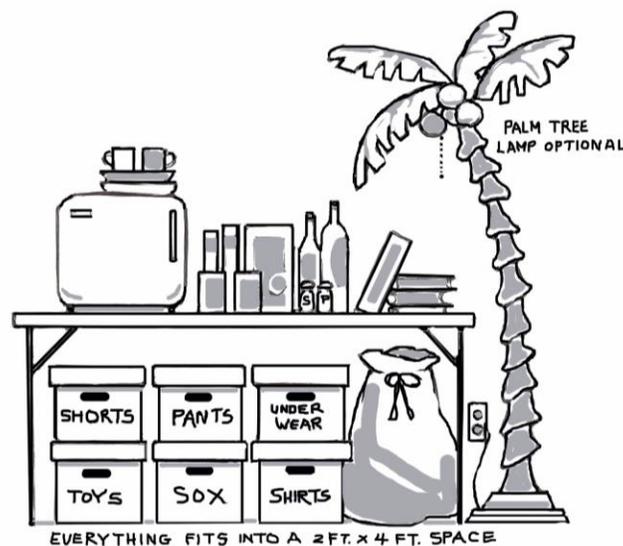


**THE AVERAGE LENGTH OF STAY IS 28 DAYS. BRING ANYTHING  
THAT WILL MAKE YOU FEEL AT HOME IN YOUR ROOM**

## MOVING INTO YOUR HOSPITAL ROOM

I always thought having one's own room in a hospital would be quite luxurious – space, quiet, privacy – well, no.

You do have more space than a semi private room or a ward,, but there's nothing in it except a bed, a chair , a little bedside table, and one of those over-the bedtable contraptions with all sorts of drawers and levels that no one can figure out how to operate. There are no shelves, closets or dressers, so you have to improvise your own. This is what I brought and it worked really well:



- Bar fridge – indispensable if you can manage to get one. You can stock it with whatever tastes good to you, since the hospital food is---um---not great. Your favourite bread, real butter, salad dressings, cold meat, good cookies, ice cream, ice cubes, popsicles, puddings, chocolate bars, whatever you love. And it's all there for you night and day.
- 2' x 4' folding collapsible table ( to put the fridge on, as well as whatever food and other stuff that can't go on the floor)
- 6 cardboard legal file boxes (in office supply departments, 3 boxes to a package) The boxes, labeled with whatever was in them, held all my clothes in separate boxes. Worked great.

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- Pillows from my bed at home Blankets from same (there are no blankets in hospital any more, only flannel sheets)
- A large comfy throw or large shawl to use while sitting in the chair \*Lots of changes of clothes see below)
- Small plastic two tiered shelf for bathroom (see unmentionables below)
- Scrub brush or shower sponge on a rope
- A laundry bag, Ziploc bags, large and small, garbage bags, large and small,
- Headband light or small table light for reading in bed, if you can find one ( the only light source in the room are overhead fluorescents or the one behind your bed, and to turn that one off you have to get out of bed and flip a switch. If you've been trying to read yourself to sleep, this is a problem!)
- A couple of extension cords (for fridge and lamp)

## **QUIET**

There is none. Bring earplugs and eye masks.

## **PRIVACY**

There is none. See below.

## **WHAT TO WEAR**

You are going to need many changes of clothes, because you will be dealing with constant diarrhea and sometimes you don't get to the bathroom in time! Buy soft, comfy (fleece) shorts, capri pants, long pants, loose tops, sweaters, and, this is very important, buy a size larger than you normally wear.

Tight clothes quickly become difficult to manage, because you will have little energy to wrestle with them, and you might have to remove them quickly.

I brought shorts, capris, pants, t---shirts, matching fleece jackets, and gym socks which had loose soft elastic tops, because your legs and feet will be swelling. I was in hospital in summer, though. In winter, you might want to bring heavier versions.

## **WHAT TO WEAR (continued)**

### **SLEEPING**

Not much. Four hours at a stretch is a miracle. Pajamas and nightgowns will probably not work. The best solution is to sleep in your clothes, which is another reason you ought to buy soft fleece things. There is no privacy, since medical staff are taking your vital signs at all hours of the day or night, and you will also be constantly running to the bathroom. Ladies, I'd recommend sports bras instead of regular ones, since you can get them in dark colours and they don't really look like underwear, and there are no hooks to deal with.

### **FOOTWEAR**

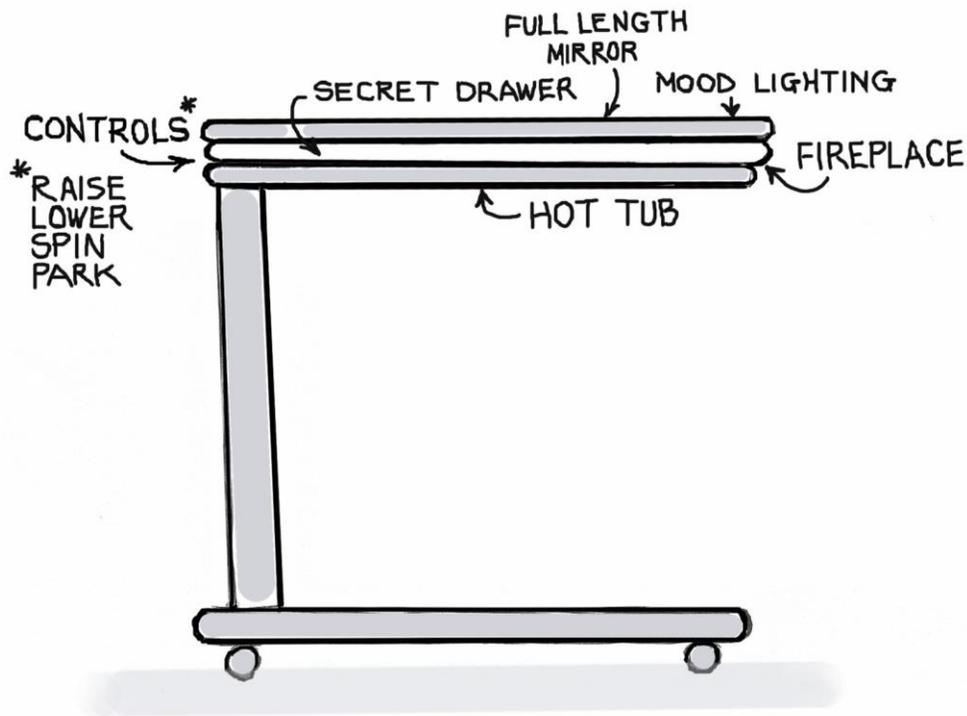
Your body is going to be swelling quite a bit, especially your feet! At the worst of it none of your regular shoes or sandals will probably fit, so I found that a sandal with a Velcro adjustable strap across my instep worked best.

### **UNMENTIONABLES**

The information sheets you get will suggest you bring some adult diapers with you. I found this advice hard to believe, but fortunately I met a former patient who told me they were an absolute necessity, and also to be sure and bring really soft toilet paper and baby wipes! I thought he might be exaggerating too. I was wrong. Those three things will loom very large in your life for a while, since the drugs you'll be taking cause constant diarrhea. It's like those sphincter muscles that have served you well since you were three have disappeared – whenever you pee, cough, gag, move suddenly --- you're going to have diarrhea, with no warning, and often you won't be able to get to the toilet in time.

There is no shelving in the bathroom, so when you select the baby wipes, find some in a rigid plastic container. The soft plastic versions are really difficult to manage when you are juggling diapers and toilet paper. A small plastic shelf unit, about 6" deep and 20" high would be a great help here. Buy the best, softest toilet paper and wipes you can find. Your rear end will need all the coddling you can give it!

\*A word about the diapers, too. Of course, I bought some of the ones that promise to be invisible under clothing, but found I couldn't use them. They were TOO fitted: what works best are the generic versions that have lots of elastic at the waist and legs. They aren't pretty, but are much easier to get on and off, and believe me when I say fashion takes a back seat in this situation!



## WHAT TO WEAR (continued)

### STAYING WARM

I always find hospitals chilly places. When going through this treatment I could never get warm – in July! The best solution seemed to be to layer things, but it is difficult since staff have to have easy access to your PICC lines for blood tests and all the other checkups require bare skin to be exposed a lot. Putting on a long sleeved jacket doesn't work, because you have to take it off all the time! I found a shawl or throw solved the problem, because it could be easily unwrapped, and also could be double layered if you are feeling really cold. Warm socks are good, and even a warm hat, especially when you try to get to sleep at night and your bare head is chilly. I'd even bring some warm mitts, since your hands can get cold too!



**YOU MUST MAINTAIN A MINIMAL LEVEL OF PHYSICAL ACTIVITY  
DURING YOUR STAY**

## ENERGY LEVELS

Well, you aren't going to have any. When you are in the midst of this treatment, even thinking is a difficult process. You won't believe the work involved in ratchetting up the energy to get yourself from your bed to the chair, or organizing yourself to go to the bathroom and to have a shower or brush your teeth. It's totally exhausting! I couldn't figure out why the staff made such a big thing about getting some exercise every day, but you will understand why when just making your bed takes half an hour.....and just thinking about doing it will tire you out first.



"It does not Matter How Slow You Go as Long as You Do not Stop"  
Confucius

## **ENTERTAINING YOURSELF**

TV service in the hospital is very expensive, so if you can bring a laptop or tablet of some sort, filled with movie channels, games and websites you are interested in, you will be able to relax a little when you can. I found jigsaw puzzles and books and crafts impossible because there is ALWAYS someone interrupting you. One day I decided to count everyone who came into my room for some purpose – not just visitors--- and I lost track at 20! That did include a gaggle of interns, but even so, you see the problem. It is also very difficult to concentrate on anything – I've heard it's called "chemo brain".



**MUCOSITIS AND/OR OR MOUTH SORES ARE A COMMON SIDE EFFECT, ALONG WITH NAUSEA AND DIARRHEA**

## **EATING**

When you are truly in the middle of this treatment, eating is really difficult, due to mouth sores or mucous (mucositis) in your mouth and throat that is, – awful. Imagine your mouth filled with a pillow covered with slime. Yes, it does go away eventually, just like everyone says, but eating is torture for days. All I could manage was green tea with meal replacement powder dissolved in it, and very cold smooth things like applesauce.. You can get all your pills pulverized by the nurse, thank goodness, and they will mix them up with applesauce for you. Nothing tastes good; anything with texture, like toast, is impossible, and even the smell of food will be unbearable.

But there is light at the end of the tunnel, you will get through it., as everyone will tell you. The first thing I was able to eat when I began to recover was Cream of Wheat, something I've avoided my whole life! It was smooth, warm, and I could mix jam or syrup into it for some flavour. So try everything you can think of that might appeal to your taste buds. This problem with food, and it's flavours and textures, lasts long after you leave the hospital, and it does take quite a while to get back your appetite. Three months later, I can't eat spaghetti with tomato sauce, because it tastes as though I've drenched the pasta in lemon juice! Lobster doesn't have any taste at all to me, and bread doesn't really have any flavour either. Anything crispy and cold does taste good, though. Like the rest of your body, it's as though your digestive system is relearning everything, and it is going to take a while.

**“When You're at the End of Your Rope, Tie a Knot and Hang On”  
Theodore Roosevelt**



**STEM CELLS BEGIN TO RETURN TO YOUR BONE MARROW AND  
PRODUCE WHITE CELLS AND PLATELETS! HOORAY!**

## **THE END AND THE BEGINNING**

I was in the hospital for about three weeks. When I got home, I didn't really know what to expect. The main things I am experiencing are fatigue, weakness, and difficulty getting my appetite back, but all that is improving every day, so all in all I can't really complain.

Thinking back on this experience, I liken it to a roller coaster ride. You "pays your money and takes your chance"! There are some very high points (when your stem cells "reattach" and your counts start going up) and some very low points (can't eat, mucositis, nausea, diarrhea, exhaustion) but you do end up at the exit gate in one piece, you do climb out of that coaster car, and off you go, on the road to your new life!

“Though the Road’s Been Rocky, it sure Feels Good to Me!”  
Bob Marley

**GOOD LUCK!**

