

## R. Ian MacLeod's (UNAPPROVED) SURVIVOR TIPS –



*In my desire to become a cancer patient advocate for those struggling with diagnosis, treatment, and recovery, I offer some (unapproved) survivor tips. I'm not a medical professional so I can't give medical advice, but I can offer a transparent and honest POV from a patient. As these personal tips are from my own experience, it means they are also very subjective as every journey through cancer is different.*

### **Tip #111 – SKINNY JEANS**

I'm 6'2' and 200 pounds. I'm a big guy by most standards. I'm not as young as I wish I was, but I'm still at the age where the possibility of wearing skinny jeans could be awesome. I would never wear skinny jeans. Not because I don't want to, but because I tried and failed miserably. I couldn't get the pants past my knees. Oh well...millennial dreams.

BUT then there was a plot twist! You are diagnosed with Leukemia in July and by the time you've wrapped up chemo, radiation, and a bone marrow transplant, you're magically ready for skinny jeans. Complete truth; this is not a lie. When I left the hospital at the end of November I weighed 145 pounds. I had lost 45 pounds. I was famished. I was a shadow/skeleton of the man I used to be.

Since none of my clothes fit when I left the hospital, my wife and I headed to American Eagle Outfitters. Do you know what they have there? Oh yeah...skinny jeans and lots of them. The best part: they are genuine skinny jeans, but they have a stretchy type denim. I got three pairs; dark blue denim, tan jeans, and black jeans. I was in heaven.

I felt terrible every day during recovery, but sometimes you can be satisfied with just looking good. I'm not saying cancer is the best way to lose weight quickly (it does work), but I am saying that you should embrace every stage of your recovery. There is nothing wrong with enjoying your present state.

When you lose your hair embrace wearing hats and beanies, when you are pressured to put on weight, eat ice cream every day, and when you have rails for legs, you wear skinny jeans and you wear them proudly.

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Then years later when you can't get them past your knees again, you donate the pants, cut back on the ice cream, and move on. At least I got to enjoy skinny pants for a season.

### **Tip #047 – ALWAYS WEAR A MASK**

The moment you are admitted into City of Hope, the mask becomes your companion. It's what keeps you alive. The mask is very uncomfortable for most as it can be suffocating or hot to the breath.

Once you wrap up your bone marrow transplant, the first 100 days become critical. You must adjust to a low bacteria diet, being at home in isolation, and always wearing a mask daily. Those are the rules, but it's not all bad though.

The one thing that got me over the 'recovery' hump when I left City of Hope was movies. I love all things cinema. It's my craft, passion, and joy. To feel better, I'd go to the movie theater several times a week, but not without a medical mask. You typically will rotate between wearing a hospital ordered mask that is yellow or green.

Soon I would discover that masks made movies WAY better! You sit down and people would collectively freak out. They politely acknowledge where you were sitting, then give you tons of space. There would be a deep bubble around you. No one would sit by you. Perfection.

At first I thought they knew I could get sick from them, but after a while I realized people thought I wore it because 'they' could get sick. Perhaps this is not true, but often there were clear signs to indicate that.

So get some popcorn and candy (when your taste buds come back) and enjoy the clear view of the screen. And remember to put your feet up on the seats in public. It might be the best movie experience you ever have.

### **TIP #122 – RADIATION PLAYLIST**

So radiation is upon you. My apologies. It's a process that most don't want to go through or have gone through. I was terrified of the unknown and the unknown can be frightening. You will throw up, you will have diarrhea and you will be uncomfortable. I'm not here to tell you the obvious.

What I can recommend is that you will need a playlist. You will need music that can generate energy, propulsion, and vision while you suffer. You will have to surrender all control in this radiation process, but you do control the playlist. That's it.

Transportation will wheel you to the radiation vault. You will get out of the wheelchair and stand four inches from the wall in preparation for your blood to boil. They close the bank-like vault, the red siren starts flashing with a loud pitch, and you try to maintain your balance by staring at glass ceilings with butterflies on them (sounds dreamy, right?). You have zero control over anything BUT the music they blast over speakers. The music will barely be heard over the siren, but it will be there.

Being a meditative person my first playlist was compiled of Buddhist/Zen music. It was in place so that I might be able to step outside myself and transcend that moment.

My first attempt was a major fail. It didn't work at all. The Zen music made me irritable to the point of wanting to scream. The anticipated lush landscapes were replaced with burning corn fields.

After getting back to my hospital bed and throwing up, I decided that it was going to take something stronger to endure. I would need music that mirrored my emotions; frustration, anger, aggression, and passion. For me I would turn to music that was always on my radar; old school hip-hop and rap. The beats informed me in my formative years in junior high and high school and motivated me in college. It was a driving force during my marathon running days.

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I had three sessions a day for five days. I had a variety of playlists with different genres, but this one was my first breakthrough.

1. Eminem - Lose Yourself
2. Young Punx - Ready for the Fight
3. Ice Cube - Vaseline
4. Public Enemy - Harder Than You Think
5. Kanye West - Stronger
6. Eazy-E - Eazy-Er Said Than Dunn
7. Common - The Hustle
8. The Roots - The Fire
9. NAS - If I Ruled the World
10. Wu-Tang Clan - Triumph
11. J. Dilla & Slum Village - Players

My father would choose Led Zeppelin and my father-in-law would choose BJ Thomas. The point is, Do YOU. You have to pick music for the battle. You need music that makes your heart want to fight a little longer. Lyrics that make you 'fight' to stay alive. The *MC confidence* that you hope to absorb through osmosis, so someday you can walk out of the hospital with swagger back to your life.

There is no perfect playlist, but the one you create for the fight. Music that will impose your will, which will motivate the survivor cells to come forth, and the passion you need to scream 'I STILL BELONG HERE! MY RESPONSIBILITIES AREN'T FINISHED.'

### **Tip #021- WAITING**

Oh, the waiting. Nothing can prepare you for the amount of waiting you have to do when you get cancer. You have to wait for results, blood work, food orders over the phone, and for a nurse to come to your need when you hit the little red button on your IV line. Nothing can prepare you for the excess amounts of doctor's waiting rooms. You suddenly feel like a character in 'Waiting for Godot,' trying to leave purgatory and return to your life.

Waiting is part of the process. The more you fight it, the more you want to throw something at the front desk (even though they are there to assist you). You know it's not their fault. It perhaps isn't even your fault, but you're the star of this production called *cancer*. So the sooner you calm down and give into the abnormalities that are now the new normal, the better off you will be.

Don't wear a watch. You can't make up the time you lose by sitting in waiting rooms. Don't try to calculate the time that can be spent doing something else because there is nothing else to attend to. There are no more appointments with 'the future' until you address the fight of your life that is in front of you in the present.

Replace the watch with headphones. Good headphones. So you can listen to good music. And get lost.

Reading material is helpful, but save the desire to read that 'epic book' you always wanted to get to. James Joyce's "Ulysses" will have to continue to wait. You won't have the patience to read a mass amount of pages and frankly, you don't know if you'll be around to finish it. That's not meant to be macabre; it's just the fact of the matter. None of us know if we'll finish what we start.

So read magazines or do what I did; start reading comic books. Not too much reading, lots of drawings to let your imagination run wild and as soon as you get to the final act of a comic book, the nurse always calls your name. Guaranteed.

## **Tip #012 – PACKING FOR THE HOSPITAL**

There will be an appointment when your oncologist tells you to go home, pack your bags and say goodbye to your family. This is rough stuff. I don't recommend the experience to anyone with a soul or feelings.

After you ball your eyes out, hug your family tightly, you dry your eyes and head into your bedroom to pack your things. To pack your bags for a walkabout you're wholly unprepared for. So what do you pack for the journey of your life? Think comfort.

Here is my necessities list:

- 1.) SWEATS – This is your official permission to wear sweats and feel okay about it. Keep the jeans and dress shoes at home. You want no pressure on your stomach area. You want to be warm, but be able to take off layers. Room and body temperatures change quickly! You have to be ready. A sweater hoodie is great, but make sure it includes zippers.
- 2.) BEANIES – You will lose your hair and your head will be cold. Not everyone will be comfortable being bald, but you want to cover your head for body heat. Heat rises...right through the top of your head. Keep it harnessed.
- 3.) LOVE MEMENTOS – Picture frames of your wedding day and your children's birth. Photos of any memory you want to relive when you've checked out mentally. You will want to get lost in these photos. Find that necklace that has your wife's initials on it. The one that you wore when you first were dating. The one that said you would love each other forever and that you would fight like hell to stay here on earth with her. That's the one you bring.
- 4.) MALA PRAYER BEADS – You don't have to be Buddhist to wear something that you can knead with your fingers while passing the time. A wise friend once said, "Do your time, don't let time do you."
- 5.) DVDs – Dust off that large case of DVDs in the back of your closet. In your hospital room they only play DVDs. Leave the expensive blu-rays behind.
- 6.) STUFFED ANIMALS - Steal the stuffed animals that remind you most of your kids, but know they won't miss.
- 7.) PORTABLE SPEAKER – Don't forget to bring your portable speaker so you can hook up your playlist. I highly recommend dropping some dough on a good portable speaker.
- 8.) CRAZY SOCKS – You can't hype yourself up when you're always changing into an open hospital gown. It's hard to get in the mood to do anything, so crazy colorful socks are a necessity. The more loud and offensive, the better.
- 9.) SPORTS JERSEYS - I'm a big sports fan so I brought all of my sports jerseys with me. L.A. Lakers, NY Giants, and Manchester City football jerseys. You may not look like an athlete in the hospital, but it is indeed the sporting event of your life. Wearing a jersey often gave me a sense of pride and a competitive edge that is very beneficial when you're fighting for your life.
- 10.) BLANKETS – All kinds. Soft ones, pink, and all colors. Anything to stay warm. Throughout chemo you will most likely come down with a fever and chills. The nurses will provide warm blankets, but they will be tan blankets that feel like paper. Get big blankets that are knitted and remind you of being a kid. You will become attached to these blankets and soon they will be your 'lovey.'
- 11.) CHRISTMAS LIGHTS - If you can pull it off, bring a string of Christmas lights. I draped my IV line with sparkly lights and plugged them into my IV pole. The IV line is a pivotal part of your identity as a patient. It becomes your life force in which you get chemo, food, and medication. Seeing bright lights around the clock made me feel less lonely.

A small confession. The nurses asked me if I had the Christmas lights cleared by hospital administrators. With a straight face I said, "Yes." They shook their heads and never asked about it again. In all transparency though...I lied. I didn't get clearance. Chemo brain makes you do unpredictable things. (My apologies!) So before you string up the lights, you may (or may not) want to ask for permission. Of course, you didn't hear that from me.

### **Tip #322 – YOUR LAST MEAL**

Stop! I'm not referring to your last meal before you die! That would be a horrible tip and too hard to decide on really. Sushi? Pizza? My brain couldn't uphold the task.

What I am referring to is the last meal before you are admitted into the hospital. At the end of my first appointment with my oncologist, he asked me, "What are you gonna eat before you're admitted?"

I was a little thrown. He then asked me what my favorite food was. I replied sushi. He said, "That's too bad. I love sushi, too. You won't be able to eat it for at least a year."

*I would later learn that my oncologist was a foodie. We would later develop a personal relationship where he would tell me when he had good sushi, delicious BBQ, or anything with bacon. It was actually very mentally healthy for me. It kept me engaged and excited for the day when my taste buds would come back (and they did!) and I would relearn to indulge in everything.*

Back to the sushi...no sushi for a year! Are you kidding me?! No wasabi. No saki salmon, no yellowtail sashimi. Nothing.

(Off the record) my oncologist should have said nothing, but he said, "You better enjoy some sushi before you're admitted tonight." He was right. If this was the last meal before I was stripped of my senses, I was going to make it count.

While I was at home packing my things, my wife was on her way to Katsuya in Studio City to pick up \$250 worth of sushi. Let me tell you...I had no regrets. Because once you start treatment you don't want to eat. No appetite, you lose your taste buds, and you're so nauseous they have to hook you up to a feeding bag. The non-bacteria diet is pretty strict, but you won't want to eat for a very long time. (Sorry to scare you!)

Presently, I'm indulging in sushi often and you will too, again. In the meantime, enjoy your last meal and prepare for the first meal after full recovery. Mine was a steak sandwich from Northwood's Inn in Rosemead...delicious!

### **Tip #089 – WHAT IS THE WORTH OF ONE SOUL?**

After diagnosis, treatment, and recovery the medical bills piled at the front door. As I managed to move about my house during recovery (a shadow of the man I used to be), the hospital bills became very discouraging. You would try not to get the mail, but what else can you do around your house?

We all know this to be true, but it must be stated; *nothing in life is free*. That's just the price of admission in life.

What's great about being an admitted patient in a proper cancer facility is that everyone is very cognizant that you are suffering and to show you a medical bill in your fragile state, you might decide it's better (and cheaper) to pass away than survive. Let us not be fooled that this doesn't cross a patient's mind.

By all means you should live, but when you're recovering in isolation and the staggering medical bills pile in, it's very depressing. The question; was it worth it? The answer is yes, but it comes with some reservations.

In the first 12 months after I was released from the hospital (in a state of remission), we finally calculated how much it cost to save my life. It's a gross amount which I won't disclose, but I will say it's enough that I could invest in real estate in my beloved California. Mind you, I didn't have to pay all of the balance because I was the luckiest man alive to have good insurance. Unfortunately, a lot of people aren't as lucky as I am and don't have good insurance. And no matter how good your insurance is, no one is prepared for a life changing diagnosis.

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Ultimately I'm not complaining about the medical cost to stay ALIVE, but I am saying that if you are a survivor (or a caretaker), you most likely will be overwhelmed by the bills. You perhaps will question yourself as a person. And I'm here to say, DON'T.

The cost was worth saving your life. People need you to remain here and just because you have debt doesn't mean you ARE your debt. What's worse than death? Perhaps bankruptcy, but you will survive that, too. If you are diagnosed with cancer and you are lucky to survive it, death is the least of your problems (in my humble opinion).