

TAKE THIS CHEMO

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To the ice cream lady from downstairs



IT'S GOING TO BE ALRIGHT...







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Disclaimer

This book is a not-for-profit endeavor written for adolescents and young adults battling cancer.

The content of this book is for educational and entertainment purposes only. It is not meant to serve as medical advice. The views and opinions expressed in this book are solely those of the patients who wrote it.





FOREWORD

The foreword was meant to be written by the cancer cells. However, they are all dead.









WELL, ME TOO

I write this book for us; for me to distract myself and reflect as I go through my treatment, and for you to learn and reflect as you go through yours.

My name is Francisco, but in the hospital, they kindly call me "The 19 y.o. Male with Diffuse Large B-Cell Lymphoma." Quite a compliment, right? Basically I am the Cancer Kid.

In the beginning, I felt very scared and stressed. I didn't know what to expect. I had so many questions. Conversations with my doctor would sound like this:













My mom will kill me if | die. Will | die, Wizard? Will | be too sick? Will | be in too much pain?





It was quite unsettling. Though I fully trusted Dr. Wizard with my life, it was so overwhelmingly scary to not know what to expect. But then one day, a volunteer named Riqui came into my hospital room and started talking to me. Riqui had also dealt with cancer before; he sat right by me and said:

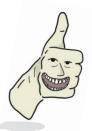
"Hey man you know what, it's going to suck, but it's going to be alright."

He then took a piece of paper and began to write down a few tips

"If you get those mouth sores, take Magic Mouthwash. That thing barely works, but it's better than nothing."

And he went on and wrote a small list of tips that helped me so much throughout my treatment. Having the advice of a former patient felt like a massive weight had been removed from my back. Just knowing that Riqui was able to go through it made me feel like I could too. It made me feel for the first time that it was doable!

At the end of my treatment, I decided to write down my own list of tips, which evolved into the book that you are holding right now...



...YOU'RE WELCOME!





I will now dive deeply into the precious lessons that I have learned throughout my treatment. I will share them with you hoping it can make your treatment more bearable. I have also included some tips from friends of mine who have had cancer as well. They have contributed their own perspective and insight, making this reading immensely richer and more useful.

Zoe Arthurson-McColl, who had Acute Myeloid Leukemia. Her tips span throughout the entire book!

Gabriel Dantzler, who had Ewing's Sarcoma with multiple relapses and head surgeries. Gabe added most tips from the Surgical Procedures chapter.

Rebecca Head, who also had Ewing's Sarcoma and had to relearn how to walk after a major leg surgery to remove her tumor. She added some good insight here and there!

But above all, always remember:



THIS IS TEMPORARY!

It's going to suck, but it's going to be all right.







0



OPENING THOUGHTS

#1

Your mentality is 90% of the treatment. You only know how strong you truly are when being strong is the only thing left for you.



BRING IT

- Respect your doctors, nurses, PCA's, everybody. It seems cliché, but you will catch yourself being a little rude sometimes due to pain or sickness. It is okay, but do not forget to apologize afterwards. We are all human beings and although you are the patient, the better you treat others, the better you will be cared for!
- "But why me?" Well, this happens, unfortunately but you are not alone! It is you because you freaking got this!
- Now you have a new schedule and a new life. The better you plan ahead the logistics of it, the fewer mistakes you will make. Meticulously establish all the details straight from the beginning, such as who will drive you to the hospital, cook for you, get your medications, and give you full-body massages.
- 5 Tip #4 is vital. Being a cancer patient makes an already stressful situation seem almost unbearable. I have passed out after waiting in the pharmacy line. You do not want to deal with any unnecessary problems, so the tip is: avoid doing things by yourself! Chemotherapy renders us unable to tolerate much.

SURGICAL PROCEPURES #1

- 6 Big tumor removal/biopsy surgeries can be super scary; all kinds of new and unique ways to feel pain. (yay!) Anesthesiologists and surgeons who you may not know may also seem scary. It's okay to be nervous and it's ok to let them know that you are nervous.
- Make sure to express all of your concerns to the surgeon. If you keep anything inside, they will find out about it as soon as they open you up (pun intended).
- On a serious note, if you feel overwhelmed by information you don't understand or anxious about the whole thing, here is some wording that I would always use:

"Would you explain this one more time so I can fully understand?"

"Can you communicate what you plan to do before you do it?"

"Can you check on me during the procedure?"

"Can you tell me what exactly to expect during the procedure?"

- In the beginning I would feel like I was bothering the doctors by asking questions or asking for them to repeat their explanations. This would only make me feel more anxious because the doctor would leave and the questions would stay. I learned to really take my time in asking questions. Remember, you have the right to know what they plan to do. Make sure you take your time in understanding the doctor's explanations and don't shy away from asking them to repeat multiple times!
- For pre-op, if they mark your body with a marker, you can take the marker and write a joke on your skin (without changing or affecting their marking).
- 11 Always have jokes prepared for pre-op, laughing surgeons make you relax.

- 12 When you wake up, instead of telling your friends that you are ok, draw Xs on your eyelids and send them a photo of you lying still instead.
- 13 Also when waking up in post-op, it is a great moment to make time travel jokes and convince the post-op nurse that you are a time traveler.
- II If you pass out or have anxiety about needles, make sure you tell them. They can do things to help you relax and not even feel "the pinch."
- 15 If you feel like your vision is turning black and you are about to pass out, tell them! Don't try to be the tough guy like I did. Tell them so at least they can get you something to drink and bite on, as well as get your legs raised for a second.
- 16 If you are reading this before a big surgery, trust me that you will be well and it's going to be alright!



SURGICAL PROCEPURES #2

- 17 If you have a procedure for which an empty stomach is mandatory, do not eat anything, please! You will try to sip some water and eat something before procedures without even thinking. Don't do it.
- 18 For lumbar punctures (spinal taps): The younger you are, the earlier in the day you may have your procedure. It also depends on the number of patients for that day. Usually, the latest you can go to the operation room is early afternoon, unless you eat or drink something less than 8 hours prior.
- 19 Also, make sure to eat very well the night before your procedure. Just don't be cheap like me. That late night cafeteria sub can really disturb your internal spirits, just saying.
- 20 Make sure to always have somebody with you during procedures! And make sure to acknowledge them and thank them for being there with you. Gratitude goes a long way in this world!
- Also on lumbar punctures: laying down for a few hours after the procedure would prevent me from getting headaches.
- You will see hundreds of physicians. Most will be great professionals, but some!!...will make you never want to see them again. Be prepared to stay calm when they frustrate you. I will never forget the doctors who helped me the most and the coldest ones as well!

#23

Having headaches afterwards? Try caffeine! ... I was reluctant at first to take caffeine for headaches, but it really helped me.

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- 24 Bring a book or something to distract yourself before procedures. You may have to wait in the pre-op-room for a long time before the doctors are finally ready.
- 2.5 Be aware of everything going through your IV. Ask them to let you know because they may not tell you otherwise. I remember receiving anti-anxiety medication even when I was completely fine. Many hospital protocols make patient care blindly repetitive, so remember to always be attentive and emphatic about your questions and wishes.
- 26 Another reason you want to know specifically what you are being given is because you will learn how you react to every medication. For example, I learned that ice cream makes me feel mentally happy, but physically fat.
- 27 One more reason? Doctors and nurses do make mistakes, so by knowing what to expect you may be able to prevent one. Look out for yourself!

#28

As soon as you are awake after a procedure, ask for a nice, cold soda. Drinking soda will be the best feeling ever. Ever. Ever.

SON YOUR SURGERY WENT WELL, I DID A PHENOMENAL JOB – BUT GOSH YOU LOOK TERRIBLE!



SURGERY RECOVERY



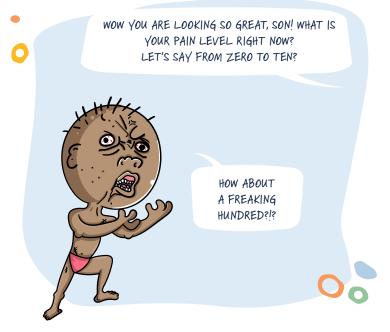
29 I have painstakingly learned some precious tips that may help you recover well from a big surgery. Having said that, all surgeries are unique, so I would ask your surgeon for some tips on recovering from your particular procedure.

#30

Those prescription pain meds like Oxycodone or Morphine can definitely help with reducing pain. However, always keep in mind that they can also make you very constipated, nauseated, dizzy, and overall sick. It's a tough balance. Wonderful nurses will guide you through it, but always be mindful of this balance.



- 31 Of course, I was not mindful. All I did was ask for pain meds for four days straight. Well, I ended up having to take this strong laxative that was just so incredibly painful. Ask your nurse as soon as you can how to avoid being constipated for days.
- 32 I highly recommend a combination of stool softener, Senna (it's kind of a plant), and good old cranberry apple juice. These you take as soon as you can (this is not supposed to be medical advice but grandma advice confirm with your medical team).
- 33 Seriously don't underestimate the power of good old cranberry apple juice.
- The person taking care of you will be as exhausted as you. Make sure you acknowledge them. It's a simple thing and it makes a huge impact in those caring for you.
- 35 If you feel like you can take Ibuprofen/Tylenol instead of the hardcore prescription pain meds, it's worth doing it. But don't worry about it in the first day or two.



- 36 If the pain and discomfort are really high, remember two things: First, it is temporary. It will pass. Two, keep breathing. Focus on each breath.
- 37 If you are recovering at home, have someone write down each med you receive, including the hour and day that you take it. Days and nights quickly become a blur, so keeping track of your meds will help you know when you can take your next dose safely. Otherwise you will end up forgetting.
- 38 Hydrate as much as possible and use mouthwash if you feel too sick to get out of bed to brush your teeth. It's good to get up for a few minutes, though. It helps your G.I. tract work.
- 39 Try to eat what you can. Maybe something light and salty. I will not name any foods here in case you are nauseated...
- Anesthesia can also have these weird side effects like shivering or overall discomfort. Just know this is temporary. You got this.

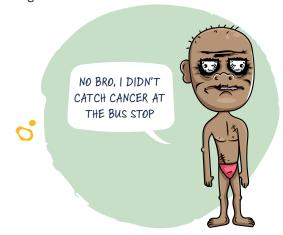
FAMILY & FRIENDS

#41

Prepare to completely reconfigure your friend list.

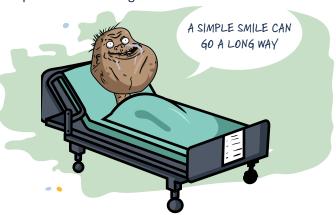
People you don't even know may become close friends and people who you are close friends with may disappear from your life.

- I felt extremely alone at the beginning. I felt as if all my friends had disappeared. You will understand that those who disappear still love you, they just don't know how to react. You will be able to understand what true friendship really is. Those who stay with you are your real friends.
- Never isolate yourself. Support from family and friends is crucial for a bearable time during chemo. My grandparents were my main ice cream suppliers gotta keep the supply chain rolling.
- It is a shock for everybody around you to know that you have such a harsh disease. They may not understand your diagnosis or your prognosis, so you may hear the craziest stuff imaginable. If you hear some nonsense that bothers you, don't worry about it. Most people will never understand what you are going through.



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- Use One or two people will have to devote themselves completely to help you overcome your illness. They may be suffering as much as you are. Never take them for granted and never lose an opportunity to say thank you.
- If you treat them very well. It's one of those obvious things that us patients tend to forget.



47 Streetlight volunteers are wonderful people who are willing to spend time with you to make you feel better. They are students who go through rigid assessment and training before they can step in your room. You should get to know them. If you are at a different hospital and do not know what Streetlight is, ask someone if there are any volunteers who can come visit you.

#48

Be friendly to everybody. Show people that you are grateful to be alive. You will be surprised by the amount of friends you will end up with at the end of the treatment!





THE BEEPING MACHINE (I.V. POLE)



- The beeping machine is the most annoying piece of material a human being could ever be unfortunate enough to deal with. It will wake you up in the middle of the night and eventually drive you crazy. But please, don't punch it (like I did).
- There is a yellow magical button that if you press it, the machine will silence for a little bit.
- **51** You can actually adjust the volume of the beeping. Set it up to the lowest.
- 52 Sometimes it beeps for very silly reasons, like air bubbles in the line, so pay attention to what is causing it to beep. My dream is to destroy one of these machines with a baseball bat. Just kidding, I would never do that...

#53

Wonderful nurses won't let it beep during the night. So when that happens, make sure to acknowledge their efforts and thank them! Simple acts of kindness will make a big difference in your care.

If you are receiving only fluids, you can ask the nurse to set you free for 10 min to take a nice shower. She may unhook you if you kindly insist. You will still have to tape a giant plastic square over your line, but you will feel so free and independent.

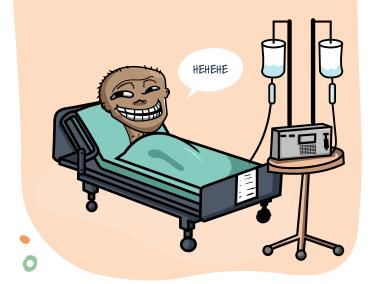
TAKE THIS CHEMO



#55

Calling the nursing station whenever it beeps becomes so annoying that you can distract yourself by joking with the staff.

She will eventually hang up on you but you will have innumerous opportunities to try to finish the song.



YOUR CENTRAL LINE

- There are all kinds of central lines. They all require dressing changes every week. These dressing changes can be annoying, but they are absolutely essential to keep you infection-free.
- You must keep it extremely clean. Extra alcohol swabs are never too much. It is a window for infections, so keep it tight and very clean all the time. (Zoe): I have gotten infections in my line a couple of times once it was so bad that I became septic and they had to remove it and put a new line on the other side of my chest. Take care of yours!
- I always preferred the small dressing with an additional piece of tape on top. Try different dressings and tapes until you find the perfect one for you. Eventually, you will get used to your central line.
- 59 For showers, I found that Anchordry™ 7x7 (the giant plastic square from tip #31) worked very well for me. This one is not that great but it was the best I could find (my hospital did not have this size so I ordered it online). Let me know if you find a better one.

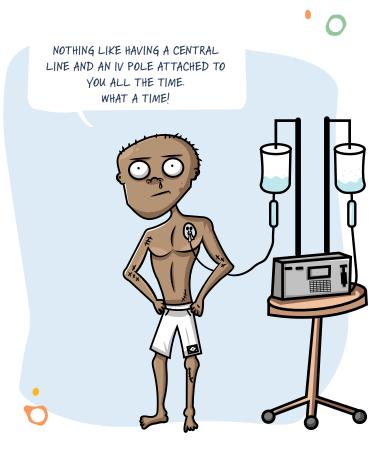
#60

Some nurses are really good at changing dressings. As soon as you find one who is, watch carefully how she does it so you can let the other nurses know the way it feels better for you.

TAKE THIS CHEMO



61 I used to be so amused and disturbed by how there was a tube coming in and out of my chest as I breathed in and out. If you are reading this and can't relate, consider yourself lucky! It was horrible. If you have one like this, make sure to protect it at all costs until it's out! It's temporary!



OUTPATIENT CLINIC

- 62 There is no specific pattern for when the clinic is full of patients. It is quite unpredictable. I would say afternoons are emptier because doctors prefer to have patients scheduled in the morning. Though you may come many mornings with no one there as well.
- 63 Bring stuff to do because you may wait for a looong time before your doctor steps in. I would always get some music going. It would help me relax and also pass the time.
- Be aware that you can't actually feel when your Absolute Neutrophil Count (ANC) is very low. It can suddenly drop so I would always wear a mask in the hospital. Masks are annoying, but you will get used to them. They are simple but they can save your life by preventing you from getting an infection. Everything you do to prevent an infection is definitely worth it.





PHARMACY

- 65 If possible, never go to the pharmacy on your own. You want to avoid exposure to a line of sneezing, coughing people. Always ask your doctors to have the pharmacy either bring your meds to you or mail them out. Otherwise, it is crucial that you have a family member or a friend picking up your medication for you.
- One day, with very low blood counts, I went to the pharmacy with my grandfather to get my medication and it took almost 2 hours. I do not know how I survived that day; I felt as if I was going to die. Avoid doing things even if there is somebody with you. Your ideal life is home-hospital, hospital-home.
- 67 Certain pharmacies on the hospital premises consistently have longer wait times than others. Ask around about the different pharmacies available to you someone might be able to tell you which pharmacy is the best to go to. Having said that, you should be able to get meds sent to you.



INPATIENT CHEMO #1

- 68 Ask your doctor/social worker for services that help you get distracted, like recreational art or art therapy. Sometimes these services (like Child Life and Arts in Medicine) can drop off art supplies for FREE! Making art can be such a relief, even if you are not artistically inclined.
- 69 Also ask for "music therapy". There are many musicians who work by singing and playing for patients. Just please don't ask the food lady to sing like I did...

#70

Ask for a Psychologist. Even if you feel completely fine, having a nice conversation with them can significantly help you. Just make sure their visit will not be out-of-pocket billing!





TAKE THIS CHEMO

- 71 You can have all kinds of videogames and movies provided by Streetlight and other organizations within hospitals. You can also bring your own books and Netflix. (Zoe): I made it my mission to watch every episode of Friends and every Harry Potter movie; it helped to distract me and also gave me a fun goal to work towards.
- 72 If you can, invite your friends to your room if you are feeling well, which may be rare. Ultimately, do anything that can keep you busy. Again: please don't ask the food lady to sing. I am traumatized to this day. It was loud and scary.

#73

During the day, always open your blinds and let the sun come in to lift your spirits. This one is really important, especially if you can't go outside.



When I arrived at the admissions desk, I learned that the rule was first come first serve. In other words, patients admitted before you may get the best room available (if they are staying roughly as long as you). So get there early enough so that you can potentially have the nicer room. This may not be the case for your situation, but it's worth asking!

INPATIENT CHEMO #2



- 75 Keep your room very clean and organized. I was never able to follow this one. (Zoe): I had an extremely nice friend who would help me tidy up my room when she visited - if you are feeling too sick to get up, don't be afraid to ask someone to help you out with stuff like this.
- 76 Remember, inpatient chemo is not a good time to deal with anybody from hospital admissions or cashier's office. If they contact you, as they did with me, kindly ask them to postpone the issue or to solve it in their office.
- 77 Bring your pillows from home. Your hospital bed already sucks, so you may as well get some comfort out of your precious pillow.
- 78 There are signs you can put in your hospital door like: "do not disturb. Only essential personnel." Ask nursing about it!
- **79** If you are receiving chemo continuously for days, ask a nurse that you feel comfortable with to take you outside for some fresh air. It will be the best sensation ever. If your counts are too low and you can't go outside, ask if someone can take you for a walk around the hospital at night when it is not busy.





- Talk to your nurses about your medication and vitals during the night. Try to negotiate a schedule in which you are able to sleep better. For example, I convinced them not to wake me up at midnight only to take my vitals. Also, I would receive my pills one hour sooner at night and one hour later in the morning so that I was able to sleep longer and therefore, better. They are so focused on your protocol that they may not notice simple things that can greatly improve your hospitalization experience. Note: some regimens do not have much flexibility but it is worth a shot to find out about yours.
- Buy a book, an adult coloring book. It does help, I promise. Or, simply go to the end of this book and you will find some pages to color. It will keep you relaxed and distracted for a little bit.
- 82 In my room, there was this extremely strong LED bright light right on top of my bed. PCA's would turn it on to take my vitals in the middle of the night sometimes, which was traumatizing. I put a big fat tape on top of the light switch, with a sign: "ask before turning it on."



NUTRITION #1

- 83 There will be times when eating healthy is one of your options, and times when eating junk is the only option. In other words, you may not be able to eat anything on one day, but everything on another, and that's ok.
- 84 Eat healthy during the days you are feeling well. Eating well will be harder and harder as you dive deeper into treatment, but you must push yourself in order to get the essential nutrients you need to recover from chemo. The better you eat, the better you will feel.
- 85 If you have to get an NG tube (NasoGastric tube), don't feel bad. It is scary, but completely normal for someone going through cancer treatment. You will get used to the feeling of it just like you get used to having a central line.
- 86 If you are too sick and have trouble keeping anything in your stomach, you may get your nutrition through an IV with lipids and TPN (Total Parenteral Nutrition). Try not to get your face too close to these bags on your IV pole though, because they smell awful.
- 87 Now, for most of your treatment, you will be sick of everything. One thing I was able to eat throughout the whole process was ice cream, which is a horrible source of nutrients, but a sacred food created by the ancient gods.
- 88 If you get sick of drinking water (I did), you can try: carbonated/ sparkling water, or low-sugar Gatorade (the light blue one), or even teas. Anything to keep you hydrated... One day I told my doctors that I was throwing a house-party from my hospital bed and asked them to bring Vodka. I am not sure they appreciated the privilege of the invitation. No one showed up except for the food lady who brought me some fine ice cream.







- 89 If you have no appetite at all, you can ask your doctor for Marinol. Don't get too excited, it's not really marijuana in pills, but it does have a synthetic version of THC (tetrahydrocannabinol) that is used for appetite stimulation. You have got to eat, so if it gives you annoying side effects, try asking for lower doses or another appetite stimulant.
- Avoid fast food from the food court. I am sure you will eventually eat there, but then when you do, you will curse chicken nuggets forever. Legend says these things never get digested... No wonder why so many people look like chicken nuggets. I am sure you have a neighbor who looks like a chicken nugget.

#91

Also avoid eating your favorite foods while you are getting chemo or are otherwise sick. If you throw up your favorite food, it probably won't be your favorite food anymore.

NUTRITION #2



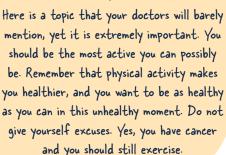
I USED TO LOVE CHICKEN NUGGETS

- 92 At home, drink a ton of water. Remember that while inpatient you may be continuously receiving fluids, but at home you are not, so you need to intake as much fluids as possible to stay hydrated and flush out medication from your body.
- 93 Eating foods that are rich in protein is vital to keep your muscle tone and overall health. Things like grilled chicken, meat, fish (never raw), eggs, and milk are all phenomenal options. If you can only eat a snack or cannot eat much, try adding whey-protein to the snack, which is also a great - and easy - source of protein.
- There are nutritional supplements that are proven to help you be healthier, like Omega-3. Some vitamins, however, can be quite dangerous because they may make side effects of chemo worse or even negate its effect. This is where the hospital dietician can really help you. Make sure to ask for a dietician, and make sure to brush your teeth after you eat!
- 95 During the first month of my treatment, the food lady was my favorite person in the hospital. Surprisingly, I used to love the hospital food. That's how bad of a cook I am. But after a while, I got so sick of it that just the smell would make me nauseated.



EXERCISE

YEAH BRO THEY PUT ME ON STEROIDSI



#96



- 97 Ask your doctor to order Physical Therapy (PT) for you. Even if you had surgery yesterday, this professional will guide you on how to feel better and how to heal better and faster.
- 98 Aerobic activity is good for your cardiovascular system. So if your doctor allows, do it. You want your heart very strong so that anesthesia goes smoothly and with no issues. Aerobic activity helped me a lot. It has been scientifically proven to help fight fatigue during cancer therapy!
- 99 Weightlifting may also be appropriate for you. In my case, I was unable to do it until I finished chemotherapy, so I lost all of my precious gains. Ask your PT about it and tell them that you want to be jacked and tanned. If PTs /OTs come at a bad time, just kindly ask them to come back later! Don't take PT for granted, though! It can really help you a lot.
- 100 Given that most gyms have high levels of microbial fitness, the best you can do is find ways to exercise at home. I bought some resistance bands and did some bodyweight workouts. You can also try other things like yoga, dance, sports, dog walks, or simply sitting up after laying in the bed for a long time. Anything that gets you moving is great, as long as you don't push yourself too much. It's good to always have someone around as you exercise.

41



- 101 (Zoe): You will have to become very comfortable discussing your bowel movements with doctors and nurses. Eventually, you will get used to it. I think nurses like talking about it.
- 102 Avoid using food-related descriptors to describe the texture and/or consistency of your poo; ask your doctors and nurses to do the same... Just saying.
- 103 Chemo causes mucositis, which can be a problem at any point in your GI tract (including the bottom part). If you feel pain down there but are not comfortable talking about it, say you have bottom pain. Doctors and nurses will know what you mean.
- 104 If you start to feel irritation and/or pain down there, try using baby wipes instead of toilet paper (then pat dry with toilet paper). They are much gentler on your skin.
- 105 If you get constipated, there are a number of things you can try, like eating a high fiber diet, drinking more fluids, and sitting in warm water. The laxatives should be a last resort because boy they hurt!
- 106 If you do have bottom irritation/pain/bleeding, you will probably have to use some sort of diaper rash cream. I had 3 or 4 at one point. Use a plastic glove when you apply it. It will feel weird, but the weirdness is worth it for how much it will help.





- 108 If that is not an option, meet with your professors to find a solution together. Consider taking independent study credits, or working out a plan that allows you to take an Incomplete in a class and then have more time to complete the required work.
- 109 I was able to finish my semester in college while hospitalized, but it was extremely stressful. I am not sure I recommend it. And if you are feeling sad for missing out on school, don't worry about it. You will learn so much about yourself, your life, and the world by going through a cancer treatment. Just work on being healthy again.
- 110 (Zoe): I was in my first year of graduate school when I was diagnosed with leukemia, and I loved (and continue to love) school. Because it was so important to me, I made it a priority to stay on track as much as I possibly could. It will be difficult to focus on studying, but it will help to set small and realistic goals. Being realistic is the key. Even if you can only read a couple of pages before getting too tired, you can still feel good about yourself for reading those pages.

MOUTH CARE

111 Chemo and radiation can sharply increase your chances of getting cavities because of acid reflux, vomit, lack of cleaning, less saliva flow, and overall weak immune system. Cavities may seem like an easy-to-fix issue, but they are not covered by most health insurance plans. Result? This can get very expensive really quick! I learned this one the hard way.

#112 (Rebecca): Make sure to always have a mouthwash next to your hospital bed in case you feel too sick to get up to brush your teeth. USE AND ABUSE THE MOUTHWASH, SON. LET IT BURN.

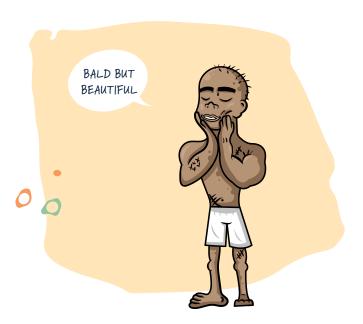
113 Make sure you use a soft-bristled toothbrush and are careful not to be too rough when brushing your teeth. Chemo can cause mucositis, which might mean that your gums bleed easily. Every time that you bleed, you are at risk of infection. But also, having your gums bleed is just gross.

- If you receive radiation in the head or neck area, it is imperative that you ask your doctor for fluoride treatment. Radiation can reduce saliva flow, which helps wash out bacteria. The drier your mouth is the less saliva flow the higher the risk for cavities.
- 115 Mouthwashes are a great tool for those times when you are too sick or too tired to stand up and go brush your teeth. With the help of somebody, you can easily clean your mouth without getting out of bed. Avoid the ones with alcohol though, because it dries out your mouth. But brushing your teeth needs to always be a priority! You may already be looking bald and sick, why make it worse by letting your teeth fall out?
- 116 Mouth sores may become the worst side effect of chemotherapy. Carafate™ or Magic Mouthwash™ can really help.
- And ultimately, for the sake of your dear mom, grandma, doctors, or any living being that may come near you: please take care of your oral hygiene! What is the point of being nice to people if whenever you smile you suffocate them with your chemo-breath?



HAIR & FACE

- Be prepared for when your hair falls out, because all of it may fall out. Eyebrows, eyelashes, everything. (Zoe's tips):
- 119 When your hair starts falling out, it will get tangled more easily. If you have long hair, be careful about leaving it in a messy ponytail when you sleep because you can end up with giant knots that are difficult (read: impossible) to comb out.
- 120 Try to have fun with it! When my hair was falling out and I got a huge knot in my hair, I made a hairball bunny with the hair that fell out when I tried to comb out the knot. I made it a home in an Easter basket and named her Florence. This might sound creepy, but who cares? Make this a fun event and not a depressive one!



TAKE THIS CHEMO



#121

If you miss having eyebrows and don't know how to draw them on, ask your friends/family if they know how — it is pretty easy once you get the hang of it, and this simple thing can help you feel more normal.

- 122 If you don't have eyelashes anymore, be careful about putting on eye makeup. It is best to avoid eyeliner and eye shadow without eyelashes, there is nothing to help keep that stuff from getting into your eyes.
- 123 If you do wear makeup, the easiest ways to get it off is to use baby oil or baby wipes. For baby oil, put it on a cotton swab like normal makeup remover then do the same with water afterwards to wipe up the residual oiliness. With baby wipes, just wipe and remove!
- Baby wipes are also good for cleaning your face in general this might not seem important when dealing with cancer, but having a clean face can help you feel more refreshed.
- 125 (Rebecca): If you have a bald head, make sure you add sunscreen on it for when you go out! (Yes I know I never thought I would need that either!)



IMPORTANT POINTS

- 126 Even if you are done with chemo, your house must be the cleanest place on earth and you have to be the cleanest person on earth. Your immune system will not recover right away, and being clean will help prevent you from unnecessarily getting sick.
- 127 Again, the ideal life for you is: home-hospital, hospital-home. You can't actually feel when you are vulnerable to infections (low ANC), so be careful. Being around large crowds of people during cancer therapy will just increase your chances of getting an infection that can kill you. Or you may just get a silly infection that will bring your counts down, which can postpone your chemotherapy. My point is: You will have the rest of your life to enjoy concerts, parties, and events. Why increase the chances of getting sick now?
- 128 Regarding subcutaneous injections: wipe your skin with an alcohol pad multiple times. This will not only sterilize the injection site but also numb the skin. Then stick the needle very quickly, as if throwing a dart, but inject the medication very slowly. Remember to use sterile technique all throughout! Your nurses can help you with that.
- 129 Learn everything you can about your illness. Learning about mine helped me understand more and suffer less.
- 130 Learn everything you can about your medication. You don't have to know pharmacology, but at least how each med you are taking helps you in general. Also, don't do cocaine.
- 131 If you need assistance with housing, food, transportation, etc, speak to your social worker. There are resources available to cancer patients and their families that can make a world of difference in your life. Social workers are usually incredibly awesome.



- 132 If there are things related to your life that you don't want to say in front of your family, try to find time and speak to your doctors in private. Trust them. With my grandma in the room, I felt that I could not talk about sex, drugs, and nuclear bombs. That would be so awkward. You can always request to speak one-on-one with your doctors.
- 133 I had one member of the medical team who did not make me comfortable. You can request for certain people to take care of you, and you can also ask if it is possible to avoid others. If you ever have a complaint about a staff member, you can ask about Patient Advocacy Services, and they will address the matter.
- However, most people working in the hospital, from the janitors to surgeons, are just very friendly and lovely. Respect them to the utmost and get to know them. There are so many incredible friendships you can form.
- 135 If you have any talent, such as playing instruments, share it with the doctors and Streetlight volunteers. You are on the stage now. Just please do not ask the food lady to sing.
- 136 Because of your cancer treatment, you will have endless scholarships available to you. Go after them! Ask your social worker about it.
- 137 Not only scholarships, but you will be blessed with all sorts of opportunities in life after overcoming such a harsh disease. You got this!
- 138 Your treatment is temporary and will make you wiser and unstoppable. Don't ever give up. Don't ever lose track of those who love you so much. Keep on moving forward!



DID YOU KNOW?

- That if you die of cancer, your mom will probably kill you?
- Cancer comes from the Greek term Carcinos, which means 'crab.'
 Someone thought that some cancer cells under a microscope looked like a crab... Now we gotta live with that.
- ★ For a long time, cancer has been erroneously thought of as an infectious disease. As time progressed, it became evident that this was not true. Cancer does not spread from one person to another.
- In 1917, researchers found that nitrogen mustard had an effect against leukemia. It is a compound very similar to the lethal mustard gas used in the First World War. Some chemotherapy drugs derive from mustard gas!
- Before 1947, childhood leukemia was a lethal disease with no treatment. On December 28, 1947, a poison called Aminopterin was first tested in the 3-year-old Robert Sandlers, extending his life by more than a year. Aminopterin opened physicians' eyes to a possible cure for leukemia. We have come a long way.
- In the 20th century, cancer surgery used to have a principle: cutting more meant curing more. It led to the development of radical mastectomies for breast cancer patients, which is a brutal procedure that is now considered obsolete.
- On September 24, 1962, a clinical trial of a new compound called VAMP was launched against blood cancers. It stands for Vincristine, Amethopterin, Mercaptopurin, and Prednisone. Are any of these names familiar to you?
- In 1964, Karen Lord, a 13-year-old girl, was diagnosed with Acute Lymphoblastic Leukemia. She was enrolled in the VAMP trial and was the first patient to ever be cured from leukemia.



TAKE THIS CHEMO



- In 1971, the Cancer Act 79-1 was approved, directing 1.6 billion dollars to cancer research and treatment.
- There are so many different types of cancer, all of which are characterized by an uncontrolled growth of a particular type of cell in one's body.
- Carcinogens are things that can cause cancer. Today, we know that radiation, asbestos, certain viruses, excessive sunlight, obesity, and smoking are carcinogens.
- Googling symptoms and diseases, in all likelihood, will be more terrifying than helpful. Don't ever let any piece of statistics bring you down.



Let me stop here because all of this writing is making me nauseated...

ABOUT THE CANCER KID

Below please find the evidence that the cancer kid actually existed, and that he was not a [insert conspiracy theory].



The cancer kid right after becoming a cancer kid. He did not know what was coming. Please don't feel uncomfortable with this graphic picture, you have nipples too!

TAKE THIS CHEMO



The cancer kid after months of chemotherapy holding his most precious asset: the finest chocolate ice cream from the ice cream lady from downstairs.



The cancer kid (and one of his favorite nurses) holding his last bag of his worst nightmare... A chemo drug named Methotrexate!!



The cancer kid smiles naively before being drugged to sleep by the people behind him.



This is why the cancer kid would always wear underwear for surgeries.



The cancer kid hugs the Wizard while surrounded by his incredibly loving medical team.



Years later, the Cancer Kid and the Wizard meet again in the same place with a lot more hair than before.



ABOUT THE BOOK

At some point during treatment, a psychologist came to see me. She was very kind, though she did not tell me that I would be charged \$200 for that visit.

After 45 minutes of calculated, psychology-like conversation, I told her that drawing was something I used to do as a child.

"You should draw again" she suggested.

See, I did not want to draw. In all honesty, I wanted some hallucinogens. Some powerful psychedelic medication to take me out of that torturously bleak hospital room. Something to make me feel like I could run again, or that I was at the beach, with the sun's heat warming my face.

"Or, perhaps, something that makes me think I am on top of a flying unicorn, shooting machine guns."

"Well, I am not sure I can help you with that, but I really think you should draw something."

I remember staring at her. Not in a rude way, but in a puzzled way. Did she not recognize my misery?

"Let's do a deal..." She added, quickly interrupting my thoughts, "If you commit to draw something by next week, when I see you again, I will then check with the doctors to see if we can give you some more meds."

"Deal" I said.

She never returned...

But I did the drawings.



TAKE THIS CHEMO



The raw drawings created out of sickness, boredom, frustration, and anger after days laying on a hospital bed.



TAKE THIS CHEMO

A Streetlight volunteer named Isabel Walker, who would later become a dear, life-long friend, came in to check on me a few days later.

"Nice drawings!" she may or may not have said.

"Nah, if only I knew how to draw people's feet and hands"

"It's fine! It just needs some context!"

Wait...What if I could incorporate "chemo tips" for future patients, just like my friend Riqui wrote me some in the beginning of my treatment?! Before I knew it, I had sketched out the first few. Isabel then scanned them all and created the first version of the book.

At that point, I knew this would one day become a prestigious New York Times Worst Seller, so I put that in a drawer somewhere and the book's existence was largely forgotten.





Years later, my younger sister Flora, who I call Almighty Flow, was studying graphic design in college.

"Hi glorious brother," she may or may not have said.

"I have a class project that involves designing a booklet. Can I use that little booklet of tips you wrote?"

Almighty Flow had revived the book, which ascended from the drawer into existence again. The project grew, incorporating many incredible people along the way. The result is what you hold in your hands today.

I hope this motivates you to make something out of your cancer experience. We do not choose the cards that we are dealt in life, but we can choose what to do about them. Don't let cancer take away your identity. There is always a way.



THE PARAPOX OF CANCER

"Men and women have waged a battle against cancer for four thousand years. In a sense, this is a military history - one in which the adversary is formless, timeless, and pervasive. Here, too, there are victories and losses, campaigns upon campaigns, heroes and hubris, survival and resilience - and inevitably, the wounded, the condemned, the forgotten, the dead. In the end, cancer truly emerges, as a nineteenth-century surgeon once wrote in a book's frontispiece, as "the emperor of all maladies, the king of terrors."

-Siddhartha Mukherjee



I read the quote above at the beginning of my cancer therapy. I let those words sit in my mind for hours as I received my daily transfusion of chemotherapy. To this day, this quote still stirs a sense of perplexity and fear in me.

In this seemingly long, unrelenting war against such an elusive, insidious enemy, I wondered where I would fit in. Do patients have a role or are we merely battlegrounds on which the medical community and cancer fight each other? Perhaps, I wondered, the fight has a different context, where patients are hostages of cancer, hoping to be freed by heroic oncologists. Or rather, could it be that patients are victims of murders that have yet to happen?

"No sweetheart," the nurse says, unhooking the empty bag of Methotrexate out of my IV pole, "You are the one fighting this disease, we are here to help you get through it and win it."

TAKE THIS CHEMO

I am used to that, I thought. I have fought my entire life against maladies and terrors growing inside of me. The first one may have been my predilection for ice cream, a battle from which I emerged as the loser. (in medical terms: an intense desire for ice cream leads to an internal neoplastic growth named advanced diffuse ice-creoma).

I have also battled internal enemies like ego, anger, judgment, selfishness, and all other maladies pertaining to being human. Not once, in fact, but many times. Though I would like to declare prevailing victory over them, it seems like every now and then, between scoops of ice cream, they sneak up out of nowhere with conviction against me.

The emperor of all maladies, I reasoned, must be the fruition of all such terrors: a "formless, timeless, pervasive" enemy known by the wisest as the final boss of the video game.

"You are all set, sweetheart. I will leave this nausea bag here in case you feel sick. At 11 pm I will be back with more meds. Can I get you anything right now?

"Thank you for your kind support; can I ask for the cheat sheet?

She stared at me unblinkingly.

"The cheat sheet for me to win against the final boss of the game, the fruition of all my terrors, the emperor of all maladies," I explained.

She kept staring, this time questioning the extent of my cognitive capacity.

"How about some water with ice?"

"That also works, thank you!"

That night would end up being the taste of the battle that awaited me. And it started with water tasting like metal. The unfolding presence of the final boss would take a few cycles of chemotherapy to creep in. But once present, it was overwhelmingly merciless. In the weeks that followed, my body began to break down from inside out, along with my dignity. High dose chemotherapy has this insidious way of erasing your identity, slowly detaching your humanity from you. Slowly removing life out of you.



TAKE THIS CHEMO

"The medicines you are receiving are meant to kill rapidly dividing cells," the Wizard once told me, "which means that they attack cancer cells, but can also attack normal cells that divide quickly, like cells from your skin, G.I. tract, nails, hair follicles, etc."

"Well, no wonder I look like Smeagol from Lord of the Rings" I thought. But then, in a moment of epiphany, the rules of the video game finally began to make sense to me: It was a matter of who would die first. It was me and my tumor competing to survive chemotherapy, surgeries, and hospitalization. Only one could be alive at the end. There was no co-existence and there was no silver bullet.

From then on, I learned that my only job was to survive longer than my tumor and that for as long as I did, I would still be in the game. Thus, no matter how unrelenting and torturous life felt, or how painful my reality was, I was still surviving. In the most difficult moments, I would bring my attention to each breath going through my nose. "I am still breathing. I am still in the game." Each breath was a step forward, an accomplishment, a reminder that I was still there.

Not to say that this would dissipate the pain, but through the pain, I would breathe and repeat:

"I am still in the game."



The paradox of cancer is a powerful realization that happens to many patients after the end of their cancer therapy. And it is quite a beautiful one:

Although the experience of cancer treatment is a painful reality that feels nothing but endless, it is actually temporary. And when it does come to its end, you carry on the appreciation for the moments when you don't feel like crap. After all, they would happen so rarely during treatment that you quickly learn to cherish them. And with that realization comes a powerful sense of gratitude for the preciousness of time and the urgency of now. Often, through scoops of ice cream, I catch myself inhaling a deep breath with such intentionality, focusing

TAKE THIS CHEMO

on the gift of still being in the game.

Often, through the craziness of day-to-day life, I feel the sunset's warmth reach my face, along with a soft tropical breeze. Now, this experience may go about largely ignored by most people. To me, it triggers a profound sense of gratitude. Whenever that happens, I am brought back to a particular day in the middle of my treatment: It had been weeks inside a cold, bleak, and artificially lit hospital room. I begged my nurse to bring me outside for just a few minutes and she so kindly agreed. As I left the doors of the empty hospital, pulling my IV pole with her help, I was hit by this breeze and warmth coming from the sunset. I distinctively remember how foreign and miraculous that felt. I closed my eyes and took a deep breath, feeling my lungs fill up with life. I was, by all accounts, as irreverent about living as I could possibly be. But at that moment, somehow, I was reminded of the gift of life. It was a simple moment of so much power.

Such deep, meaningful appreciation for trivial moments like this happens to individuals who have been to the edge of the abyss, and who have contemplated the darkness below. It happens to those who may have all the reasons for irreverence and nihilism, but who, somehow, find in those reasons profound meaning and appreciation for life. That is the paradox of cancer.



As for the remainder of my life, I will continue the fight, but rather than in the hospital, in the research laboratory as a scientist. Though I cannot offer you the silver bullet, I humbly offer this book as your cheat sheet to overcoming the final boss.

Keep breathing, you are still in the game.





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What tips did we forget to mention? Would you share them with us?

Scan this QR Code by pointing your phone's camera at it!



WHAT ARE YOUR MEMES?

Show the inner memes that you have stored in your brilliant chemo-brain mind.

WHEN YOU... arrive in the hospital for another cycle of chemo...







WHEN YOUR HAIR FALLS OUT BECAUSE OF CHEMO...



TAKE THIS CHEMO

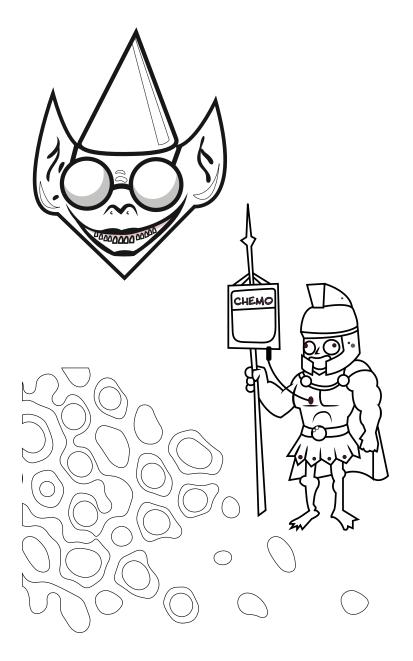
ME AFTER A FEW MONTHS OF CHEMO...

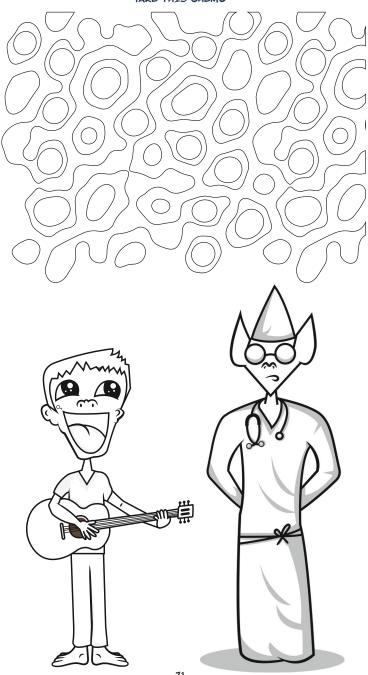


DOCTORS BE LIKE...



COLORING BOOK





THIS I MUST NEVER FORGET AS I GO THROUGH CANCER TREATMENT





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TAKE THIS CHEMO



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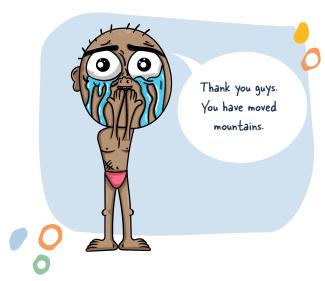
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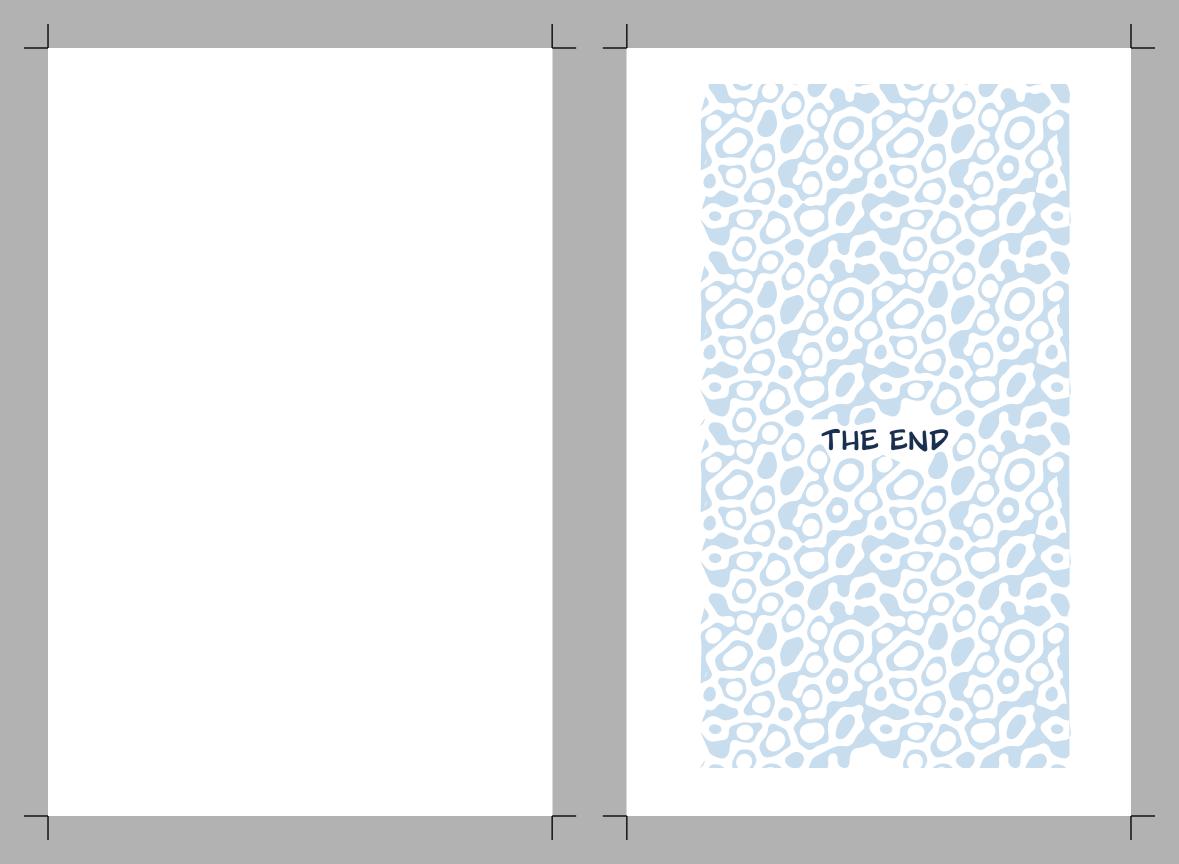
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Proof