

The **LIVE NOW** club

# Expecting the Unexpected

Lou's Guide to Cancer

A NOTE FROM ME

*I write this recognizing that every cancer is different, every body is different, and every experience is different. I wanted to share a practical guide to things that helped me get through the worst of it (though I'm not quite done yet), along with random tidbits I wish I'd known going into it.*



## Table of Contents

<b>Core Principles.....</b>	<b>3</b>
<b>Before You Start Treatment.....</b>	<b>7</b>
1) Build Your Care Team.....	7
2) Reduce the Information Flow In.....	9
3) Control the Information Flow Out.....	9
4) Prepare Your Home for Healing.....	12
5) Set Up Your Daily Logistics.....	13
6) Body Prep.....	15
7) Build a Safety Net.....	18
8) Prepare to Stay Proactive, Not Reactive.....	18
9) Quick Start Checklist.....	19
<b>Treatment.....</b>	<b>20</b>
Overall Advice.....	20
External Beam Radiation (Pelvic).....	20
Chemotherapy.....	21
Brachytherapy (cervical cancer specific).....	23
<b>Support Your Body During Treatment.....</b>	<b>24</b>
Circadian Rhythms.....	24
Nutrition.....	24
Hydration.....	26
Movement.....	26
<b>Survivorship.....</b>	<b>27</b>
Rehab.....	27
Grief.....	27
Sexual Health.....	28
Therapy.....	28
Scanxiety & Follow-Up Care.....	29
<b>How do you support a friend with cancer?.....</b>	<b>30</b>
What to say (and what not to say).....	30
How to support in real life.....	31
How to support/give gifts.....	32

## Core Principles

### **1. YOU NEED AN ADVOCATE THROUGHOUT THE ENTIRE PROCESS**

The most important advice I can offer is that you need to have someone (ideally the same person) who can sit next to you during doctor appointments and help you keep track of medications and symptoms. They could also be the same person who helps you with meals and home errands, or you could ask a group of friends; this isn't the moment to be proud and independent. You may be able to handle it all for the first several appointments. However, I think it's constructive to plan for the worst. How can you ensure that you can be fed and make it to appointments in the case that you are too weak to move? It's best to start in the framework that you want to end up with. If someone doesn't immediately come to mind, check with your hospital on patient advocate services.

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### **2. DO WHATEVER YOU CAN TO COMPLETELY AND TOTALLY STAY IN THE MOMENT**

Don't think about what six months from now will look like, don't think about what's happening outside of your physical sphere. Do whatever you can to keep your blinders on and focus on one foot in front of the other.

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### **3. PLAN FOR THE WORST, HOPE FOR THE BEST**

Not to be morbid, but if you think about the worst possible situation or a situation where treatment is substantially more difficult than you could have imagined, what infrastructure might you need to support yourself? How will you communicate your needs to the people who love you? It's essential to come up with a plan before you start treatment, working backwards to ensure you will have what you need. Who will take you to appointments? Who can help you get and organize meds? What will you do for meals if you aren't physically able to make it to the grocery store?

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Who can you turn to spiritually and emotionally if times are bad? And so forth.

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## **4. GIVE YOUR BODY THE BEST POSSIBLE FOOTING**

Try to keep your weight steady and your muscles working. There is a lot of literature on fasting before chemo, and after going down that path, I wouldn't recommend it. It's unbelievably important to keep your weight up, eating whatever you can. Small walks, gentle stretching, and fresh air and morning light (or light therapy) can make a difference in your outcome. Block out the latest fads and trends and focus on everything you can to take care of yourself and maintain strength.

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## **5. SHARE WHAT YOU'RE GOING THROUGH**

This may sound counterintuitive and uncomfortable for everyone, but I highly recommend it. Friends and family don't know how to help unless you tell them. It allows your community to express how they feel about you. Sharing gives your community a way to express love and support, and it can be surprisingly healing on both sides. Talking about what's happening helps your brain and body process the trauma, instead of storing it for later. You don't have to share everything, or with everyone, just enough so you aren't carrying this alone. While it may be tempting to think that you can muscle through this on your own, you're doing yourself, your friends, and your family a disservice. If you have always been a fixer or a giver, this is a valuable opportunity for you to learn how to receive.

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## **6. YOU MAY NOT GO BACK TO WHO YOU WERE, BUT YOU MAY END UP AS SOMEONE BETTER**

Going through an experience like this gives you a perspective that not many others have. This will put you on a different track, but it's not necessarily a bad track. I found a lot of solace in leaning into differences rather than feeling discouraged about not being back to myself.

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## **7. SURVIVORSHIP CAN BE HARDER**

Treatment is hard, but I found survivorship harder after my first round. Give yourself time and space to recover and relax after if you're able to. For family and friends, it's just as important to be there after treatment as it is during. It's taking me a while to get closer to a normal place.

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## **8. COUNT YOUR BLESSINGS**

Every time I felt sorry for myself, I met someone whose cancer experience was horrifyingly worse. It didn't erase my pain or invalidate my suffering, but it helped me put it all in perspective.

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## **9. THIS PROBLEM ALREADY EXISTED, BUT NOW YOU KNOW, AND YOU CAN WORK ON A PLAN TO ADDRESS IT**

A friend said this to me at the start of treatment, and it really stuck with me. Whatever was happening in my body was already happening. The difference is that now I know. Knowing gave me information, agency, and options. It enabled me to turn fear into something I could look at directly and act upon. This mindset helped me at the start and also when anxiety around follow-up scans crept in.

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## **10. FACING YOUR MORTALITY HELPS YOU LIVE MORE AND BETTER**

Everyone is going to die. You may now have more clarity on how. My mom said this to me at the start of my experience, and while it shocked me at the time, I realized how much wisdom those words contained. When you're faced with the realization and recognition of your own mortality, you start to appreciate how fragile and beautiful life is. You stop wasting time on people who drain you or projects that don't light you up. You are cognizant of what matters to you. None of us can extend our time, but we can shift our attention. You can't choose the circumstance, but you get to choose the meaning. And now that it's happened, you can use it to build a life that feels true and deeply, and wildly alive.

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*If your friend or family member has cancer, scroll to the bottom for my tips on how you can best be there for them.*

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## MY CONTEXT

To give you some context, I found my first treatment for Stage III cervical cancer (five weeks of Cisplatin, external beam radiation, and hospitalization for brachytherapy) significantly harder than my second systemic treatment for Stage IV (six cycles of 21 days each of Carboplatin, Abraxane, Avastin, and Keytruda). I am also on an experimental therapeutic peptide vaccine.

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## Before You Start Treatment

### 1) Build Your Care Team

Choose your hospital/doctor

Cancer staging and protocols are universal, but doctors take small (and life-changing) liberties through the treatment process. It's an art and not a science. We moved to New York to be at the best possible hospital with the best doctors for cervical cancer.

- Reach out to the main phone line on hospital websites to set up consultations.
- My best advice is to start when you'd want to end up - in the best possible care in case anything were to happen.
- I would recommend choosing a hospital with a cancer-specific ER. Not all of them do, and it makes a massive difference if you need it.

Be realistic about clinical trials/concierge doctors

The majority of clinical trials are not available unless you've failed 'standard of care' treatment (likely chemotherapy and/or radiation).

There is potential for 'compassionate use', n-of-1 care, expanded access, targeted trials based on mutations, but these typically become an option later, when you and your team know more about how your cancer responds.

Concierge doctors and experimental therapies can absolutely play a role, but they are not a shortcut around the hard part. Standard-of-care treatments are often the fastest path to shrinking or controlling the disease so that you even qualify for something more cutting-edge.

Consider second opinions

Cancer care and recommendations are all standardized nationwide based on the grading of your cancer, but some doctors may interpret your scans differently if you are borderline.

- Make sure you get the actual slides from the lab to expedite review by other hospitals.

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Designate your advocate and primary support person

Ideally, you will need one person who will be there with you for every appointment. Some hospitals offer patient advocates as a service. I found it very difficult to process or remember anything that doctors said during our meetings. They will provide notes after, but it's helpful to have someone in the room with you at all times.

- My mom primarily played this role for me and has been unbelievable, but my family also jumped in to support.
- This person should be aware of your overall treatment plan and needs.
- Ideally, this person can also help you manage medication.

Identify backup support roles (transport, food, meds)

You will need to consider how you get to the hospital and set up a system for meal trains and support.

- Some friends have used CaringBridge and Meals on Wheels for this function.
- A lot of people will show up for you at the start of treatment, make sure you plan for midway and later in the treatment. It's not that people don't care; they just get busy with their lives.

Find a mentor with your cancer type

We were fortunate to have a few contacts who had also recently suffered from cervical cancer. It was very useful to have someone to trade notes with on their exact experience.

- If you don't know someone, I would recommend reaching out to Immerman's Angels.

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## 2) Reduce the Information Flow In

Mute the noise

There is a LOT of noise out there about alternative cancer treatments and cancer cures that do not have a scientific basis. Many of these treatments have not been proven effective and may not apply to your specific type of cancer.

- Designate one friend or family member to field these suggestions (or set up a separate email account to consolidate these).
- Chemotherapy and radiation may be barbaric, but they are effective and proven therapies.
- There is a lot of intrigue about novel and new therapies, but they are not proven yet, and often not available until after you fail the standard line of treatment.

Do not go down a Google rabbit hole

Do not look at statistics. You are not a number. It's helpful to be realistic about what you are facing, but do not let it define you.

Take a break from social media and the news.

I found it very helpful to reduce my intake of anything that wasn't about my health or directly tied to my getting better during this time.

- You don't want to disconnect yourself from the world (see next section), but you want to take care of your mental state.

## 3) Control the Information Flow Out

Come up with a communication plan

I appreciate and understand the desire to go through this on your own. At first, I thought 'I'm strong enough,' 'I've been sick before, 'I can handle this, and so forth, but here are a few things I've learned along the way:

- It could be much harder than you expect: Neither you nor the doctors will know precisely how you will handle each treatment round. Think about what you will need in the worst-case scenario. Think about how your friends may feel if you don't share it with them.

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- People don't know how to show up for you if you don't tell them: Everyone wants to support, but no one knows how to unless you share what you need.
- Helping helps the helper: People want to show up. It allows them to feel close to you and gives them a sense of purpose during a time when everyone feels powerless.

## Plan for continuity

When you are first diagnosed, everyone will want to help, but to ensure people are there for you when you need them most, it's crucial to provide frequent updates.

- It's helpful to have a friend at this stage who can jump in to provide updates when necessary.

## Respect your energy

Worth mentioning that I found it exhausting to have visitors. I am usually a very social person, but I lost the capacity to hold space for others during treatment. I preferred to receive outreach digitally.

## Establish your framework

There are a number of things to consider:

- How will you deliver updates?
- How can you manage conversations? You may not have the energy to manage conversations with all of the well-wishers.
- What can your friends do so you know you're loved and thought of during treatment?
- Where do you need them to help you?

## MY 'WE LOVE LOU' SUPPORT SYSTEM

My mom made sure that my core needs (appointments, food, errands) were met, so I just needed love, amusement, and support from my friends. I set my system up in the following way:

- Substack - public updates, I find writing very therapeutic, and it calmed me down to know that if something adverse happened during treatment, my story would still be out there
- WhatsApp - private updates. I created a WhatsApp community for my friends with multiple channels:

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- Announcements Channel - Admin posts only
- I created a Google Doc with Cancer FAQs - all of the questions about my treatment, doctors, etc. that I didn't want to talk about but that people often asked.
- Moments of Joy (photos only, no text) - Everyone. I stayed off social media for the entirety of my treatment, so I loved this.
- Poetry, Short Stories & Other - Everyone. Space to share short poems or short things to read.
- Resolutions - Everyone. I thought it would be fun if anyone wanted to take on challenges alongside me.
- Lou Flock - NYC/SF - Everyone. City-specific groups for local friends to convene.

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## 4) Prepare Your Home for Healing

I liked having different 'spaces' around my home where I could go to make it feel like I was moving around, even though I really didn't have the energy to move far. This is what helped me a lot:

### Bed

- Soft sheets: Your skin may get very sensitive. Avoid anything scratchy. I prefer soft linen sheets.
- Noise machine: Someone gave this to me, and it was a godsend for NYC
- Eye mask: I love to sleep with a loose weighted eye mask to calm me down. If I'm traveling or in the hospital, I also have one that fastens to my head to block out light.
- Weighted blanket: It's been a game-changer for me to reduce anxiety.
- Heating pad: Comforting during cold spells from anemia

### Bathroom

- Maternity pads and diapers (cervical cancer only). I bled a lot.
- Non-scented organic lotions and creams. I became more sensitive to scents during treatment.
- Aquaphor for radiation burns.
- Soft toothbrush. I found that my gums got more sensitive.
- Dry mouth mouthwash: Some chemos give me dry mouth, so I recommend staying ahead of this to avoid mouth sores.
- Ditch the razor: Certain chemotherapies cause you to bleed more heavily, so I avoided shaving during treatment.

### Space to watch TV

#### FIELD NOTE

*I thought I could get through cancer just by reading, and that was a colossal mistake. I spent a lot of time watching TV.*

*I loved the Great British Baking Show, Derby Girls, Gilded Age, and Drops of God.*

You want to find a mix of shows where you don't need to follow the plot and ones that are fully immersive, depending on how you're feeling.

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Space for projects/reading

It's nice to have an outlet. Painting supplies, drawing supplies, journaling stuff. I barely got through a whole book, but I liked being able to read part of a chapter of something whenever I had energy.

## 5) Set Up Your Daily Logistics

Establish a plan for transportation for every appointment

Ensure you are always covered with support at every appointment, ideally from your advocate or friends.

Meal support

Set up a meal train or grocery service. Make sure you are stocked with bone broth and other comforting and nutritious foods.

Medication organization

- I keep my meds instructions in the Notes app of my iPhone, but a shared Google Doc with your advocate could also be helpful here.
- You will likely be given several different types of medicines for side effects.
- Pillboxes help you stay organized.

Prepare your ER "go-bag"

I was at the ER every week during my first round of treatment, and barely went during my second. I think it's variable, but it's best to be prepared.

- Regardless of the reason for your visit, it will likely be a lengthy stay. My hospital had a dedicated ER for cancer patients, which made a massive difference for me

Have a bag ready to go with core essentials:

- Noise-cancelling headphones
- Something to entertain yourself: Books to read / iPad to watch movies/computer / audiobook, or podcast
- Ginger nausea chews
- Snacks, protein bars
- Fuzzy socks

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- Blanket (optional, they will give you one, but I like to have mine for comfort)
- Overnight essentials (you never know): Eyemask, Toothbrush/toothpaste
- Wear comfy clothes. I lived in my cancer uniform (next section).

## 6) Body Prep

### Egg freezing

If you wish to have this future option, doctors will recommend egg retrieval as soon as possible, so as not to delay treatment. This, unfortunately, was not an option for me. But here are two places that we found along the way: CCRM, Chick Mission

### Get your cancer uniform

I lived in sweatpant sets and simply rotated through multiple colors. It was a great relief not to have to think about what to wear, and also to wear something that could be easily washed.

- Ideally, you want something that doesn't have metal anywhere (so you can just wear it straight into radiation appointments)
- I did not get a port in the first round, so it was just important for me to be able to roll up my sleeves easily for IVs
- For the second round, when I had a port, I wore low-cut tank tops and a cardigan.

### Decide if you need a port

#### FIELD NOTE

*If the option is given to you to get a port, I would recommend it. I didn't get one, and knowing what I know now, I wish I had.*

I ended up needing a lot of blood transfusions and additional hydration, and every single time, I required a new IV stick. By the end of treatment, my veins were scarred and difficult to access; nurses sometimes needed 3-4 attempts to find a working vein.

A port is a small device (about the size of a quarter) placed under your skin, usually just below your collarbone. It connects to a large vein near your heart. Once it heals, you barely notice it's there, and you can shower, swim, and go about your normal life. It requires a minor surgical procedure (outpatient, usually local anesthesia with sedation) and carries a risk of infection or blood clots.

### Do a photoshoot (I'm serious)

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I did two photo shoots before I first started treatment. I wasn't sure what I would look or feel like after. It may seem very silly in the moment, but it helped me a lot mentally when I was at my worst to know I had documented my past self. When I lost my hair, I also did another photoshoot to remind myself that I could be beautiful in any situation.

Find a masseuse

Find a masseuse with oncology experience. They need to be gentle, and it's best to check with your oncologist before getting a massage, but it helped me a lot.

Find an acupuncturist

Acupuncture helps minimize the effects of treatments significantly. I've used it to reduce nausea, neuropathy in my hands and feet, increase my energy and strength, and so forth.

Get ice booties and gloves

Not every chemotherapy causes neuropathy. Check with your oncologist to see whether yours does.

- To prevent this, I wore booties and gloves filled with ice packs during relevant treatments. These can be purchased on Amazon.

Prepare for hair loss (if relevant)

Not every chemotherapy causes hair loss. For the ones that do, hair loss typically begins 2-4 weeks after your first chemo treatment. Ask your oncologist what to expect with your specific regimen.

COLD CAPS

I chose not to wear a cold cap for a couple of reasons:

- It added significant time to my therapy
- There was still less than a 50% chance of my keeping more than half of my hair. I preferred to be completely bald rather than to have random bald spots.

WHAT DO YOU DO WHEN IT FALLS OUT?

When I made a decision not to have a cold cap, I cut my hair short before treatment started. It helped make the transition less jarring.

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When hair dies, before it falls out, it becomes straw-like. It's incredibly unnerving. Try not to touch it too much and wash it with gentle shampoo.

About four weeks into my treatment, I decided to shave my head. I found it to be incredibly liberating.

## WIGS AND HEAD COVERINGS

- Your head will get cold without hair. I often wear a hat when I go outside as a result.
- If you want a wig, get fitted before you lose your hair so they can match your natural color and style.
- You ideally want a human-hair wig versus acrylic (most costume ones)
- The wig should fit snugly with a velvet band. Custom wigs can be made with different cap sizes, depending on the size of your head and the length of your neck

## EYEBROWS, EYELASHES

I've found that I can get away with being bald without looking sick as long as my eyebrows and eyelashes are strong enough.

- I recommend getting a brow pen that matches your hair color
- Your hair will fall out in stages, so you have time to practice how to apply realistic hair strokes. It doesn't happen all at once.
- I have not had much luck with fake eyelashes, but I have found that eyeliner helps.

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## 7) Build a Safety Net

Create your mental bubble

Do whatever you need to do to mentally put yourself in a bubble. The treatments are brutal, but you are fighting the same war as chemoradiation.

CALMING MUSIC PLAYLISTS

I love ambient: Nils Frahm, Brian Eno, Hiroshi Yoshimura

Plant music playlists

RETURN TO YOUR BREATH

Box breathing

Meditation - I use a couple of different apps (for different purposes):

- Joe Dispenza (you can buy meditations online)
- Expand by Monroe (go-to for meditations, they have several health-specific ones)
- Calm (bedtime stories, emergency calm meditations)
- Waking Up (philosophical discussions on life)

Identify therapist support early

If you don't already have a therapist, I think it's essential to find one, especially one with experience with cancer.

- I was too exhausted to speak with mine for most of the treatment, but was very grateful that they checked in frequently.

Establish spiritual / church connections

It was a great help to know that I was in people's prayer circles and to have someone to speak to about spiritual matters.

- If you're not well enough to make it to a church, most churches offer livestreaming.

## 8) Prepare to Stay Proactive, Not Reactive

Speak up early, often, and loud if needed

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You are the expert in your experience. If something isn't right, speak up. Here are some examples of how:

- Bring someone to appointments who takes notes and asks questions
- Track symptoms daily
- Ask "What does success look like for this round?"
- Know your escalation plan: "What gets me sent to the ER?"
- Understand when to expect scan results and decision points
- Advocate for comfort (nausea, pain relief, hydration. Don't suffer in silence)

Start parallel path planning

Stay proactive about the path ahead. Ask a friend or family member to help you here.

- You can pursue the best treatment now and quietly plan for what may come next.
- Get genomic/tumor testing done early.
- Keep a running list of trial options for later (many require standard of care first)
- Build relationships with specialists and researchers in your cancer type
- Revisit options each scan cycle

Treat the cancer you have today. Prepare for the cancer you might be facing tomorrow.

## 9) Quick Start Checklist

- Choose a care team
- Advocate assigned
- Second opinion + slides requested
- Communication plan active
- Home comfort zones set
- Meal + transport support arranged
- Med organization system working
- Go-bag packed

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Emotional/spiritual support in place

## Treatment

### Overall Advice

- Request as much preliminary information as possible about what to expect.
- Ask what the worst week will look like and any side effects
- We found most hospital handouts too high-level and benefited greatly from using AI chatbots.
- Request morning appointments if possible - These have been shown to increase the likelihood of better outcomes and help you with better energy regulation
- Check supplements + alt therapies with oncology (Radiation in particular is sensitive: avoid antioxidants, hyperbaric oxygen, IV vitamin drips, red-light therapy unless cleared)

#### FIELD NOTE

*Your job is survival, not stoicism. Speak up, do not be afraid to ask for help. Ask for nausea, hydration, and pain control before you're desperate.*

## External Beam Radiation (Pelvic)

### WHAT HAPPENS

These are (most likely) daily targeted sessions. They are very quick and painless in the moment.

- I found it soothing to play my favorite music while treatment occurred. Your primary job is not move. You won't feel anything during the session.
- The doctors gave me tattoos on my stomach to more accurately line up the machine and made a mold for me to lie in so I wouldn't move.

### WHAT IT FELT LIKE FOR ME

- Week 1-2: I didn't think it was that bad
- Weeks 3-5: Exhaustion and nausea hit me like a truck
- Burns develop gradually (external and sometimes internal)
- Because of the location of my radiation, I was unbelievably nauseous by this point

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- Pelvic radiation may affect the bladder and bowels

## WHAT HELPED ME

- Get your appointments first thing in the morning.
- Wear clothes without metal, so you don't need to go through the hassle of changing.
- Put on Aquaphor at the first redness. I applied multiple times a day.

## Chemotherapy

### WHAT HAPPENS

You arrive at the hospital, and they infuse you with several pre-medications to help with nausea and your chemotherapy infusion(s).

### WHAT IT FELT LIKE FOR ME

- Day 1-2 = deceptively fine. I took my best naps and got work done on these days due to steroids.
- Day 3-7 = the dark woods. It will peak as the steroids wear off on day 3 and then slowly taper.
- This cycle gets harder as treatment goes on.

### WHAT HELPED ME

During infusion:

- I used ice gloves and booties to prevent neuropathy. This is not necessary for every type of chemotherapy.
- You do not need to wear these the entire time; you want your hands and feet to be cold, but you don't need to get frostbite.
- I liked to bring my blanket with me to have something familiar, but the hospital always had warm blankets.
- Ginger chews to mask the taste of pre-medication
- Something to distract yourself: I liked to meditate or listen to music during treatment
- I did not get a port, but knowing what I know now, I wish I had. I ended up needing a lot of blood transfusions and additional hydration.
- Ask for additional hydration before and after chemotherapy to reduce the toxic effects.

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## NAUSEA

The majority of ways to curb chemotherapy nausea are all off-label. I would recommend getting them all from your doctor and trying them. Do not look up what the actual usage is online or any of the side effects. Just trust me on this.

- Ativan was the thing that reliably helped me.
- CBD gummies helped a bit. Just get everything and see what works best for you.
- Do whatever you can to reliably eat meals at the same time every day and keep your calories up.

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## Brachytherapy (cervical cancer specific)

### WHAT HAPPENS (MAY BE DIFFERENT FOR YOU)

- You go under sedation or anesthesia
- A device ("applicator") is inserted internally and positioned against the tumor area
- You are not allowed to move, sometimes for hours, sometimes overnight
- Radiation teams roll you to scanning and dosing rooms with the device in place
- You may have a catheter, compression cuffs, IV lines, a pain pump, and oxygen

### WHAT IT FEELS LIKE

#### FIELD NOTE

*Not to be trite, but it feels like being raped by a cactus while being pinned down on your back. It's horrific, but highly effective.*

### Pain from the needles inside of you

- Deep internal ache
- Anxiety around immobility

### WHAT HELPED ME

- Make sure you have an advocate with you to ensure you have enough continuous pain meds. Ask for continuous, not just the self-administered pain pump.
- The pain is short-lasting. The treatment itself is harsh, but I did not have as much pain after as I did with external radiation.
- Audiobooks > TV shows (too much visual input can be overwhelming)
- An adjustable arm or clamp to suspend a tablet so you can watch while lying flat
- EMDR therapy after I finished. I found it unbelievably triggering for previous sexual assault.

## Support Your Body During Treatment

### Circadian Rhythms

#### WHY?

One of the most unexpected things I learned during treatment was how disorienting it can be to your internal rhythms. Between naps at odd hours, hospital lighting, and the stress of it all, I found myself completely disconnected from time.

Your circadian rhythm plays an important role in immune function, healing, digestion, and mental health. Research is early (but promising) that the time of day has a significant impact on the success of the treatment.

#### DAILY FIXES

- Try to get natural light in your eyes within 30 minutes of waking.
- If you're in a darker climate or stuck indoors, I used a new novel light therapy lamp for an hour each morning while eating breakfast or journaling.

#### TREATMENT TIME

Your treatment time matters. It sounds small, but the hour you receive radiation or chemotherapy can affect your body's reaction.

- If you can, unless you are a night owl or have a substantially different circadian rhythm, I recommend pushing for morning appointments. Early research studies have shown they are correlated with greater treatment success.

### Nutrition - During Treatment

Your primary and sole focus should be to eat what you can eat. Do not worry about nutrition or following an anti-cancer diet. You need to get calories in.

- Antioxidants in food are okay, but you do not want to take additional supplements if you are undergoing radiation treatment. Check with your oncologist.
- Cancer treatments cause gas and bloating.

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My acupuncturist recommended the following diet to limit additional gas, but you should do whatever you need to do to keep your weight up:

- No dairy products, no beans or nuts or seeds, no brown rice, only sticky rice, no wheat products or grains, no raw vegetables, just cooked vegetables, no carbonation in drinks, and no alcohol, no processed sugar, please drink plenty of water.

## FASTING BEFORE TREATMENT

All evidence on fasting before treatment is very early, but the treatment is at risk if you lose too much weight. It's not worth it.

## THE IMPACT OF TREATMENT ON THE DIGESTIVE SYSTEM

- Ask your oncologists whether the treatment will impact your digestive system or your ability to eat.
- What is healthy = what you can digest.
- Chemotherapy, radiation, and the associated meds can also cause diarrhea and constipation. Ask your oncologist for recommendations tailored to your specific treatment.
- Chemotherapy may change your taste buds. I would recommend not eating any of your absolute favorite foods at the start of chemo because it may take a long time to get back to them.
- Bone broth is a great way to get nutrients. One of my cancer friends loved milkshakes. Do whatever you need to do.
- I liked everything as plain, odorless, and tasteless as possible.

### FIELD NOTE

*For several weeks during both of my treatments, I have had to revert to a BRAT (banana, rice, apple sauce, toast) diet. The notion of "healthy" is less relevant than what's digestible. If you're having digestive problems, focus on a low-residue diet (cooked vegetables, proteins, white starches). As you feel better, you can slowly start to add in more fiber.*

## NOTES ON NUTRITION IN RECOVERY

- Once you are a few weeks out from treatment, you can start to think about an anti-cancer diet.
- My nutritionist helped me a lot with supplements to rebuild my gut
- I've had a lot of success with a low-glycemic Mediterranean diet.

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## FIELD NOTE

*Low-glycemic doesn't mean cutting out all sugar. It reflects the glycemic load on your body. You can look up the glycemic index and glycemic load of most foods with ChatGPT. To bring the glycemic load down, add protein and fiber. Never eat a carb alone, and always try to walk after meals to help your digestion.*

## Hydration

- Cisplatin caused me to have some kidney problems, which caused an electrolyte imbalance. I recommend no-sugar, salt-based electrolytes (like LMNT).
- Due to my light-headedness, I asked for additional hydration between cycles.

## Movement

- Try to move as much as you can each day. This could range from a long walk outside to stretching.
- Studies have shown the benefit of aerobic exercise every day, but depending on your treatment, that can be hard to do.
- You need to avoid stillness becoming stiffness.

## Survivorship

*There's a strange quiet that arrives when actual treatment ends. The machines are no longer beeping, the appointments slow down, the adrenaline that carried you through the worst of it disappears, and suddenly you are left with yourself. People will congratulate you. Your body will feel like it's collapsing. Both can be true.*

## Rehab

### WHAT TO EXPECT

- It's unlikely that you will bounce back to normal immediately. It's taken me a few months to regain my energy and mental clarity.
- Fatigue and brain fog can persist for months
- Your body may feel unfamiliar or unreliable

### WHAT HELPED ME

- Physical therapy can support if you were in a wheelchair, if you lost muscle from treatment, if you have neuropathy, or if your gait feels unstable.
- Acupuncture
- Gentle, consistent movement
- Recognizing that it's not about returning to who I was, but learning to live with the body I have now.

## Grief

### WHAT TO EXPECT

Grief arrived for me after treatment was done and when the adrenaline wore off.

- I found myself grieving the person I was before cancer, the life I thought I was living, my sense of bodily safety, my fertility and future family plans, the ease I once had with health, all of the plans I had missed over the last few months.
- It was startling to be "done" but not feel better. I felt grief for my past self and the future that suddenly felt uncertain.

### WHAT HELPED ME

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- Naming the losses out loud, journaling without trying to resolve anything, talking about it with friends and family, letting grief exist without forcing gratitude, not trying to fix it, but letting it flow through me

## Sexual Health

### WHAT TO EXPECT

- I found I had a changed relationship to my body immediately after treatment. I had, and continue to have, a lot of fear around intimacy and vulnerability and pain and discomfort.
- If your treatment puts you at risk for early menopause, these changes can come quickly and feel disorienting.
- Dilator therapy is necessary and painful at first
- Pelvic tissues may feel tight, fragile, or unfamiliar

### WHAT HELPED ME

- Ask your oncologist if your treatment puts you at risk for early menopause. If so, depending on your cancer, they may be able to support you with hormone replacement therapy.
- Treating dilator use as a ritual, not a chore. Play music, breathe slowly, no rushing.
- Letting go of any timeline for "getting back to normal."

## Therapy

### WHAT TO EXPECT

Cancer leaves psychological imprints long after the body stabilizes.

Many survivors experience PTSD, often without realizing that's what it is.

- I had strong reactions to hospitals, blood, needles, and medical smells, anxiety before scans or appointments, sudden emotional flooding or numbness, hypervigilance around bodily sensations, and difficulty trusting my body again.
- Blood and hospital ceilings were particularly triggering for me

### WHAT HELPED ME

- EMDR was transformative for me in processing medical trauma
- Working with a therapist experienced in cancer specifically

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- Naming triggers instead of avoiding them
- Sharing my experience - it was unbelievably therapeutic for me to write a book during this period about my entire journey; it helped me let everything go and move past it.
- Accepting that my recovery included psychological rehabilitation, not just physical

## Scanxiety & Follow-Up Care

### WHAT TO EXPECT

- I found myself having anxiety that spikes days or weeks before scans. I don't know if this ever gets easier.

### WHAT HELPED ME

- The mantra, "This problem existed before, now we will get information, and we can address it." Knowledge is power. Knowing early is power.
- Control the controllables
- There are some blood tests that you can pay for outside of insurance for faster results when possible.
- Having a post scan plan - I feel a lot calmer going into scans when I am very clear about what the various outcomes could entail.
- Ask your oncologist about what they're expecting to see and the next decision points. It helped me to think about my various next steps and focus on parallel planning.

## How do you support a friend with cancer?

I am eternally grateful to everyone who showed up, sent a note, or was there for me in any way. It really helped me feel like I wasn't alone in this journey. But when your friend or family member is diagnosed, it's hard to know what to say. You want to help, but you're afraid of doing the wrong thing.

### FIELD NOTE

*To be honest, there is nothing better than a consistent 'Thinking of you, no response needed' - perhaps add a photo of you in better times or something you think you'd enjoy. A couple of friends did this to me weekly, and it made my day every time.*

Please don't feel offended if you don't receive a reply. Thoughtfulness and consistency mean the world.

I found visitors exhausting during my first round, but I welcomed them during my second. Other people may feel differently. But you need to be attuned to what the sick person needs, not vice versa. They won't have the energy to entertain as they may have been able to previously.

- Be available in case they want to talk or have a visit, but don't push for it.

## What to say (and what not to say)

### WHAT TO SAY

- I love you. I'm here.
- I'm thinking of you every day.
- I don't know what to say, but I want to be with you in this.
- Can I take something off your plate this week?
- What do you want to talk about?
- Do you want to talk about it, or should we talk about something else?
- [Insert something that will bring them joy]
- Nothing - just sit there and let your friend or family member rest

### WHAT NOT TO SAY

- At least it's 'insert silver lining.'

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- Have you tried 'insert miracle cure'?
- My distant relative had cancer and cured it with 'insert miracle cure.'
- You're a fighter / you've got this one / you're strong - This has nothing to do with physical strength.
- How did it happen? What is happening? - Do not ask for specifics unless offered. It is traumatic to replay the same story and line of questions constantly. Don't presume that they did something wrong to get it.
- How is the treatment going? - They likely don't know. Depending on the treatment, they may not know for a few weeks or months after. Don't ask.
- You look great! How are you feeling? - This can be triggering. It's easier to say 'It's nice to see you' or 'It's nice to be with you.'

### How to support in real life

- Show up consistently, not just in the beginning. Especially show up towards the end and after treatment.
- Be cognizant of your own health before seeing someone undergoing cancer treatments. When unsure, err on the side of being cautious and wear an N95 mask.
- Offer specific help
- Be mindful of their energy. I got drained after fifteen minutes. Be hyperaware and sensitive to their body language and eye movements.
- Respect digital boundaries. Texts can be less draining than calls.

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## How to support/give gifts

I was unbelievably touched to receive gifts; it was very meaningful for me and helped me a lot during treatment, especially when other ways of showing love, such as physical touch and quality time, were challenging.

When sending gifts, you can view it in terms of Maslow's Hierarchy of Needs. Until someone's basic needs are covered, it's challenging to focus on anything else.

### PHYSIOLOGICAL NEEDS (BASICS)

- Home-cooked meals (freezeable or easy to digest)
- Bone broth, electrolyte packets, or snacks they like
- Soft pajamas, cozy socks, or a heating pad
- Unscented lotion, lip balm
- Eye masks
- A cozy blanket to bring with them to appointments
- An acupuncture appointment (check first)
- A massage appointment (check with them first, the masseuse should have oncology experience)
- Noise-cancelling headphones or an iPad if they don't have one, for time in the hospital

### SAFETY AND STABILITY

- Help with logistics: rides to appointments, walking the dog, groceries
- A go-bag for ER visits
- Setting up medical spreadsheets or appointment reminders. Supporting with managing medications. A fun pillbox

### BELONGING AND LOVE

- Regular texts ("No need to reply, just thinking of you")
- Handwritten cards
- Voice notes, silly memes, love letters
- Record a song or a poem for them
- Build a music playlist for them
- A record player - someone sent this to me with records, and it was a thoughtful gift

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- Flowers (or plants, so they last!)

## ESTEEM AND CONFIDENCE

- Photos of them with friends to look through
- My family gave me a digital photo frame and set it up, which was great
- A surprise photoshoot before treatment
- A comfy cancer uniform set
- Jewelry

## SELF-ACTUALIZATION

- Travel watercolor set or other portable art supplies
- Magazines
- Legos / puzzles
- Writing or journaling kit
- Poetry, short story, or art book
- Online class or subscription to something they love (nothing that requires full attention)

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*You can't choose the circumstance, but you get to choose the meaning. And now that it's happened, you can use it to build a life that feels true and deeply, and wildly alive.*

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