



Chemotherapy – a BAYS primer

So you need chemotherapy. It's scary and unfair. There are, however, many people who have completed chemo before you and picked up some lessons along the way. These tips may serve as a guide for you and ensure you're prepared for what comes next.

Please note that this is not medical advice and should not substitute talking with your healthcare team about chemotherapy.

Prepping

- Ask your healthcare provider if she has a binder of chemo resources with the drugs you'll be on, their possible side effects, and ways to manage them. This might help you get the necessary over-the-counter drugs in advance so you have them on hand.
- If your healthcare provider has not discussed chemo's impacts on your fertility, please ask him for further details.
- Consider asking to tour the infusion center to get a feel for what it's like and what resources they have on hand (e.g., snacks, reading materials, chair comfort).
- Ask your doctor to complete a form that will get you a temporary handicap parking placard, that you then take to the DMV for processing.
- Practice asking for what you need—rides, prescription pick-ups, grocery runs, childcare, an exercise buddy, housecleaning, laundry. As this can be overwhelming to coordinate, consider having a friend set up a Mealtrain.com or LotsaHelpingHands.com for you to request the help that you need.
- Ask your healthcare provider what free services they offer. This could include consultations with a dietician and exercise consultant, yoga, acupuncture, massage, guided imagery, breathing technique classes, or art therapy. They may also recommend other services offered by local or national organizations. For example, CancerCare can help coordinate rides, and Cleaning for a Reason offers a free housecleaning.
- If you are working through chemo, be ready for the days and times where you don't feel well and consider seeking flexibility with your job and an open line of communication with your boss and Human Resources. If you want to know more about your workplace rights, the organization Cancer and Careers has helpful resources.
- If you're on a chemo where your hair is expected to fall out, consider getting your hair cut shorter before chemo starts or in the early days of treatment to help with the adjustment. At some point when hair starts falling out, you might completely shave your head. There are newer treatments called cold caps that are becoming more available to help prevent complete hair loss during chemo; this may be something to ask your healthcare provider about (specific recommendations on the use of these caps are at the end of this document!). Several salons offer free haircuts for people starting chemo and when your hair starts to grow back after chemo.

- When it comes to wigs, discover what is right for you—no wig, a wig that matches your old hair, that's work-appropriate, and/or fun and colorful. Some people use this opportunity to try different looks, while others decide going bald is more comfortable than wearing a wig. If you decide to purchase a synthetic or human hair wig, consider purchasing it before your hair falls out so that the stylist can match your hair and the salon can cut and style the wig accordingly. Some insurance companies cover a portion or the full cost of a wig, and American Cancer Society provides 1 free wig for patients. Either way, many patients find comfort in wearing soft warm hats while they are at home or sleeping. Others also find beauty and comfort in the many scarf, wrap and hat options.
- Recognize that chemotherapy is a marathon. Its treatments can be cumulative and everyone's reactions can be unique. Endurance and patience and following the doctors' instructions or challenging them when they are unhelpful are core.

The day of chemo

- Think about how you're getting to and from the appointment. Arrange a ride or have supportive friends or family drive you to and from chemo. Depending on what you want, they can stay to keep you company or quietly support you (e.g., get snacks and water) while you're hooked up to the IV.
- Bring things to do to pass time—books, magazines, a journal, loaded iPad, music, scrabble games to play with your company, a neck pillow, noise-cancelling headphones, and anything that helps. While you might get drowsy with some of the medicine, you also might want to be distracted.
- Be prepared with foods and drinks you might want. Bring a refillable water bottle so that you drink plenty of fluids and snacks that might tide you over or help with nausea. Many find that eating before chemo is helpful to calm their stomach. Some steroids or pre-meds can make patients ravenous, so having access to food right there is helpful too. Think about what you like to eat when your stomach is upset and plan for that; crackers, bananas and fruit, and other neutral foods that don't have strong smells tend to work best.
- Wear something so that the nurses can easily access your veins or port *and* something that you're comfortable in. For some, this is yoga pants, cardigans, fuzzy socks and a cozy hat. For others, this is business attire. Or maybe this is simply colorful or fashionable clothes that make you feel good. Consider ease of using the bathroom while hooked to an IV too and wear bottoms that are easy to get up and down. Also, most infusion centers have warm blankets if you get chilly.

During and after chemo - managing side effects and self-care

- Develop a relationship with the office staff or phone nurses at your healthcare provider. They can be called frequently about some new, even if seemingly small, side effect (e.g., I sneeze for 48 hours after chemo). They can often look at a photo of the side effect (like a rash), talk you through it, recommend over-the-counter medicine to address it, call in a prescription, or ask you to come in. **Speaking up is important to get you comfort and care.**
- Relatedly, communicate with your doctors. They can only help you if you tell them what is going on with your body and mind.
- If the anti-nausea medicines they're giving you aren't working, ask for a different one. The field has developed much-improved anti-emetic drugs.
- Recognize that side effects are different for everyone and each day can be different for you. Beyond new prescriptions, there are often over-the-counter medicines that you can take. For example, for bone pain, Claritin D, heating pads, and warm baths; for constipation, smooth move tea and Senakot laxatives. For neuropathy, Glutamine powder. Home remedies can be helpful too (e.g., for diarrhea, a combination of bananas, rice, applesauce, tea and toast; for constipation, a combination of prune juice, wheat bran and applesauce). Taste changes, dry mouth, and mouth sores all have simple

suggestions easily found online (e.g., mouth sores may be helped by honey or papaya and avoided by brushing with the toothpaste Biotene).

- Expect pre-med steroid side effects that may include weight shifts, sleep disruption, or mood swings. If the steroids are disabling you from sleeping the night after chemo, for example, you could ask to adjust your future dosage.
- Explore complementary care to help manage side effects. This might include acupuncture, massage, medical marijuana, Qigong, and mind-body techniques like meditation and guided imagery.
- Wash your hands often and try to prevent cuts that could become infected. The combination of frequent handwashing and chemo can dry out the skin, so finding a good moisturizer like coconut oil or badger balm for your skin and nails is helpful.
- Hydrate constantly with water, flavored water (e.g., cucumber, citrus, and basil), Gatorade, or something else that replaces lost electrolytes. Even gelatin, popsicles, broth or ginger ale can hydrate. If you're a bad drinker, you can also ask for extra saline fluids before and after your chemo; this extra hydration can also help with nausea.
- Regarding eating, find what works for you. Some people advise avoiding anything raw because of your weakened immune system and the fact that raw vegetables are more difficult to digest when your stomach lining is being sloughed off through chemo. Strongly-odored food can be upsetting too. Others recommend eating bland food like oatmeal, pudding, mashed potatoes, and noodles and having high quality vegetable, chicken, or beef bone broth on hand in case you are unable to eat. Some suggest staying away from foods that you really like so that you can enjoy them again after chemo without any negative associations. Most people agree to try and eat something right before or at the beginning of chemo so as to avoid the drugs hitting an empty stomach.
- Avoid alcohol during chemo, as your liver is working extra hard to process the chemo and may be overly taxed with alcohol.
- Recognize that you will learn how to conserve energy and handle fatigue, really listening to your body and prioritizing what it needs. It might be explained in this analogy: you are being handed a limited number of quarters each day to spend; choose carefully what you spend them on because when they are gone, they are gone. When your energy is gone, stop and rest.
- Exercise as much as you can through chemo, finding what works best for you—walking, swimming, yoga, anything with movement. Exercise combats fatigue, boosts your mood, and helps you sleep. Having an exercise buddy can help motivate and keep you accountable to get off the couch.
- Sleep, sleep, sleep, and get comfortable with the possible re-introduction of a nap in your life.

ⁱ If you choose to use the cold caps, here are recommendations on how to prepare and administer.

- Stop coloring your hair or doing other damaging processes. While the cold cap manufacturers often recommend not cutting your hair, cutting your hair may make the fitting of caps easier and regrowing simpler.
- Ask about how comfortable the infusion center staff is with cold caps. While it is not in the infusion center staff's job description to help you with the cold caps, it is important to know if they are tolerant.
- Ask if they have refrigeration space or if you'll need to use your own home freezer.
- Dry ice adds to the cost for each infusion. Locate several dry ice stores ahead of time. If you are using your own refrigeration and dry ice, you will need ample refrigerator space to store them between infusions.
- Speak to the chemo caps company representative and ask all of your questions.
- Find two to three family members or friends who can help you during chemo sessions. There is a learning curve to putting the caps on and switching them out, and the more comfortable your team is, the better your results will be. Even consider practicing ahead of time so you get the kinks out of the process.
- You might consider bringing additional supplies like an electric or warming blanket, infrared thermometer, hammer (if using dry ice), gloves to handle the cold caps and dry ice, cooler(s), and of course, something to do during chemo. If using dry ice, the best gloves to bring are those used in barbecuing, with long cuffs to keep from inadvertently touching the dry ice and getting hurt.
- Follow directions for use provided by the manufacturer. There are several types of cold caps, each with their own instructions.

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- The cold cap has to be placed on your head firmly to be effective, so strap them down tight.