

Everything You Wish You Had Known...about chemo:

Although some advanced chemo is now given in pill form, most chemo drugs involve IV delivery. For some women, that means a regular IV, started for each treatment. For others, that will involve surgical implantation of a port just under the skin, which will be used to draw blood for labwork and to deliver the chemo. Your oncologist should let you know what to expect; if they don't offer that information, go ahead and ask.

Most women who have had breast surgery are told to avoid lab draws or IVs in the side of the surgery as a lifelong precaution, but check with your own surgeon whether this might pertain to you.

If your chemo will be delivered via IV, be sure to hydrate well the day before so that your veins are easy to find and stick.

You can use an over-the-counter or prescription cream to numb the skin over a port. It's best applied an hour before chemo or a blood draw, then covered with a piece of plastic wrap to hold it in place.

A typical chemo day involves drawing labwork, a quick visit with your oncologist, and then the infusion itself in the infusion lab. The first chemo round usually takes multiple hours because each drug is given very slowly to see how your body does with it. Later ones may be shorter—all depending upon the specific drugs being given and how they affect you. Your pre-chemo teaching visit should cover this, but it's something you can ask about to help with your planning.

Ask your oncologist when you should stop taking vitamins and supplements (typically, several days before and after each infusion). You may also be advised to avoid some nutrients around the chemo dose time to rob the tumor of dietary support. An oncological naturopath (integrative medicine specialist) can also help you with supplements and timing during treatment and recovery.

Ask your chemo nurse for a printout of the information sheet for each of the drugs you're getting if you don't get them in a pre-chemo teaching session.

If at *any* time during chemo infusion you feel in *any* way odd, call your nurse and let them know. Many uncomfortable reactions can be squelched if you report them early.

Don't minimize symptoms: be realistic in how you feel. Ask for what you need rather than hope it'll be offered. For example, don't say "I can't sleep;" say "I need something to help me sleep."

Because the fluids given with chemo drugs are room temperature, which is cooler than your body, it's easy to become chilled during treatment. Many people like to bring a special blanket to snuggle up in.

Remember when you dress that, if you have a port, your nurse will need to be able to get to it to attach the IV tubing and that you'll be sitting in a public space with it attached throughout each treatment.

Since all of that IV fluid typically means at least one trip to the bathroom, it's good to dress in clothing that is easy to manage one-handed or while encumbered by whatever type of IV you'll have.

Most infusion labs have snacks on hand, but it's perfectly fine if you want to bring something special. A water bottle can help you stay hydrated (important during chemo!). Some people like to bring strong-tasting mints or ginger candies to help with the odd taste caused by the tube-flushing fluid used between drugs. Some people want normal food; others want flat ginger ale or cola and crackers. What your own stomach may want is

something you'll learn at your first infusion. It's all trial-and-error, so try a small amount of something to see how it goes. If something sounds like a bad idea, it probably is.

Bring lip balm and hand lotion. At home or during infusions, moisturize your skin generously. Watch closely for signs of skin infection and seek treatment immediately. Protect sensitive fingers and toes if you lose your nails.

Bring something to occupy your time. That might be another person to talk with (or to massage your feet during chemo), a handwork project, a movie to watch, or a light book to read. Please bring earbuds if you plan to consume media with sound, since other chemo patients around you may be napping.

If you just want to sit by yourself and perhaps doze, that's fine too. You may find that an eye shade and earplugs help with that plan. It's better to bring too many options for that first visit to find out what works best for you.

Anti-nausea drugs are WAY better than all of those old scare stories you've heard. Typically, we get some anti-nausea medication in our IV during chemo and some (pill form) to take at home. Anti-nausea drugs work best when taken when you first think you *might* be getting nauseated, so take them early and take them as often as you need to. If the first drug you're given isn't enough, ask for another, whether in the infusion lab or at home. Nausea can be controlled, but it's important to get on it right away.

Not all home anti-nausea drugs have to be pills. If you can't face swallowing a pill, there are dissolving versions and suppository versions that might work better for you. Ask.

It's also important, at home between chemo doses, not to let nausea, vomiting, or diarrhea make us dehydrated. When we reach a point where our urine is darker than "medium yellow," it's time to call in and ask how we can manage our fluid needs better or whether we should schedule an IV fluid top-up. Being well-hydrated helps our bodies move the chemo where it needs to go and then out of our bodies, plus it really pays off in making us feel better.

Your pre-chemo teaching should also cover why and when you need to call your doctor between visits. If this isn't offered, ask for specific guidelines, not just "if you have any problems." When we've never had chemo before, how do we know what's a problem? Your oncology practice will have someone on call around the clock, so don't feel you can't get help if it's after office hours. If you're in doubt: call. It's always better to be ahead of the curve with side effects than behind it.

Just can't face the idea of a whole glass of something to drink? Try getting a shot glass and setting a timer for 15 minutes. Every 15 minutes, throw back a shot of water or juice. That's often below the level of intake that will trigger nausea or vomiting, but can be just enough to keep from getting dehydrated.

Constipation often follows chemo doses, so a high-fiber meal rather than a steak for dinner the evening before chemo may be more comfortable when it finally emerges.

Your pre-chemo teaching session will go over special precautions you may need to take with diet and household activities to avoid infection risk. Beyond that, though, there are other things we can do to prepare. It's common for our sense of smell to become stronger and perhaps change, much as our sense of taste does during chemo. For that reason, some women choose to switch to unscented toiletries for the duration of chemo. If nothing else, this helps prevent later associating the odors of your favorite products with the way you felt during chemo.

For the same reason, it can be good to avoid our very favorite foods during chemo, just so that the altered taste of them doesn't forever change them for us. While we regain normal taste and smell after chemo, some of these associations may be much longer-lived and many women have stories about foods or beauty products they never want to taste or smell again.

The "Everything You Wish You Had Known" series is available at <http://www.womenlisten.org>

What will you want to eat during chemo? There is nothing more individual, and it often changes from dose to dose. Some of us want only very bland foods, especially if we have an irritated mouth; others may be fine with spicy but need to avoid the greasy. Some of our food yearnings may be unusual for our general taste and diet. There's just no predicting.

In the hierarchy of things we should consume, fluids tops the list, then nutrition if we can manage it, but in the end, whatever we can eat is better than nothing. Some women gain weight on chemo and others lose it. So long as it doesn't go to an extreme, that's probably okay. We can take up regaining our previous weight or improving upon it once treatment is done. And if we're indeed having trouble maintaining a safe weight, oncology practice dietitians are a great resource for suggestions and advice.

Some things that women in the group found helpful with poor appetite included: Thai food, almond butter on apples, cottage cheese, roasted sunflower seeds on Rye Krisps, organic baby food, baked apples, protein powder drink mixed with fruit, warm soups, lemon water, chilled mandarin oranges, suckers. Eating smaller, more frequent meals may help, and so may eating first thing in the morning.

Most of us associate hair loss with chemo, but in fact not every chemo agent causes hair loss. Your doctor or chemo educator can tell you whether that's associated with the chemo you'll be getting.

There are many options for dealing with hair loss from chemo. You might want to use a cold cap (ice bath for your head during chemo to prevent chemo from getting to your scalp) to try to prevent hair loss; you might want to shave or clip your hair when beginning treatment so you don't have to fuss with it; you might want to just wait and let it do its own thing.

It's worth noting that chemo hair loss means *all* hair: head, eyebrows, eyelashes, nose hairs, beard, pubic, and body hair. The upside: you don't have to risk cutting yourself shaving during chemo. Cornstarch can be helpful if body parts become uncomfortably sticky without hair, especially in hot weather.

The decision on covering your head during chemo hair loss is a personal one. Some group members say it was important to wear something for warmth at night (a lightweight knit or fleece beanie is good for this). Sun protection when we're outdoors is another good reason for a head covering. If you're working through treatment and want to protect your privacy, you may choose to have a wig made from your own hair or wear a realistic wig, while non-realistic wigs can be a fun wardrobe addition. Anchorage has regular scarf-tying classes (see your cancer navigator's office for schedule) so you can try out those looks. Many women like the bikers' skull caps that can be ordered online in a riot of different prints and fabrics. Even women who go bare-headed most of the time may find that they sometimes want to cover up when they go out, just to keep people from treating them differently or approaching them for uncomfortable conversations.

Scalp skin is delicate. Using a facial cleanser and moisturizer on it rather than any sort of body scrub can help protect it. If you're using a cool cap, be extra-gentle with your hair and scalp.

It generally takes three to ten weeks for hair growth to resume after the last dose of chemo.

Chemo effects and fatigue are cumulative, getting stronger with each cycle. It's common not to want to take that last treatment, especially when everyone wants to celebrate that you're "done" and you know you still have to go through one last spell of recovering from it.

Chemo effects are very individual, so you will become your own science project. Keep a daily journal of how you feel each day, what you did, what worked and what didn't, along with your temperature and whatever other data your doctor has requested. This will be useful in each following infusion cycle as it can help you predict

The "Everything You Wish You Had Known" series is available at <http://www.womenlisten.org>

what your typical progression is and better guide your schedule between doses. Bring it to your infusion appointments as it's also a great memory aid for when/how bad/how you coped with side effects in reporting them to your doctor.

“Chemo brain” is real. Write notes. Favor light entertainment and humor, especially things you can pick up for short periods and then put down again.

Accept help from others. Doing this is a gift to them and to you. People who love you feel powerless and want to do something to help. Ask for help even if this is not something you typically do, when you need to conserve your energy for healing. Ask people to do specific things for you (cooking, housework, help with children and pets, transportation to appointments, shopping, visiting, etc.). Only you can determine how much or how little you can manage from day to day. Allow yourself to say no when you need to.