



CHEMOTHERAPY

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Disclaimer: Our material is not intended as a substitute for medical care. However, it can be used to formulate questions for discussion with your physician. Each medical condition is unique. If you have questions about your unique condition or about information you see here, the Breast and GYN Health Project strongly advises that you consult your physician.

CHEMOTHERAPY: What is it?

Chemotherapy literally means “drug therapy”. In the context of treatment for cancer, it includes the use of many different kinds of medication to kill cancer cells and/or control or attempt to stop their growth. These medications are given by a variety of routes, but most often are given either as an “infusion” (also called intravenous, which means injected into a vein), or orally (by mouth). The medications travel through the bloodstream to reach cancer cells in the body. Chemotherapy is given in cycles, with each period of treatment followed by a recovery period. Treatment usually lasts for several months. Chemotherapy is usually started within 4-8 weeks after surgery. If you have estrogen/progesterone negative (ER/PR-) breast cancer, every effort is made to initiate therapy within eight (8) weeks of your surgery. These are guidelines only and may vary depending on your personal circumstances.

PREPARING for your first visit to the medical oncologist.

The doctors who treat cancer with chemotherapy are called medical oncologists. Before your first visit with your medical oncologist, you might want to consider consultation planning (offered by BGHP) to help you prepare a list of questions for your appointment. It can be helpful to have someone accompany you and assist in taking notes for your first visit there. If you are thinking you would like a tape recording of your consultation, ask the medical oncologist if he/she is comfortable being recorded. If they are agreeable, a “practice run” is advised to ensure that the recording device is in working order. Perhaps you can delegate this task to a support person who will accompany you to this appointment. Also, while you are at the medical oncology office, ask to visit the location where chemotherapy will be given so that you know where to go and what to expect when you arrive for your first session.

Important information for you to take to your consultation appointment with the medical oncologist is a complete list of all medications, including all prescription and non-prescription drugs, any OTC (over-the-counter) preparations, vitamins & minerals, herbal or homeopathic remedies, and other substances. This is very important, as some of these can interact with chemotherapy in adverse ways. Having this information may allow your physician to help you find substitutions where adverse interactions are suspected. It is also helpful to let your medical oncologist know if you are receiving any complementary or integrative therapies, e.g., acupuncture, massage, nutrition therapies, etc.

TREATMENT: Pre-planning

Make an appointment to see your dentist at least 2 weeks before starting chemotherapy. It is important to have your mouth as healthy as possible. Having your teeth cleaned and completing other dental work is highly recommended prior to starting therapy. Be sure to tell your dentist that you have cancer and about your treatment plan. You might consider putting your dentist in touch with your oncologist.

Ask your surgeon and medical oncologist about a “port-a-cath” before you start chemotherapy. Sometimes just called a “port”, this checker size device is inserted under the skin and into a blood vessel in order to administer chemotherapy without having to put in an IV every time. The decision to get one is often a joint one between your surgeon and medical oncologist, depending on the chemotherapy regime or “recipe” best suited for your cancer, the projected period of time for your therapy, and the status of your veins, i.e., are your veins difficult to locate or painful to access? Do you have an intense dislike for needles? PICC lines are also an option; PICC stands for Peripherally Inserted Central Catheter, a form of IV (intravenous) access that can be used for a prolonged period of time. It is an alternative to central venous catheters with fewer long term side effects. (See information at BGHP on “ports” and PICCs.)

Ask your medical oncologist for prescriptions for oral and sublingual (under the tongue) anti-nausea medications. Have these prescriptions filled and on hand before your first chemotherapy treatment. You may ask the pharmacist to give you a “partial fill” prescription for your medications to see if they are effective for you. Ondansetron ODT placed under the tongue, not swallowed, is very effective for many patients.

Consider attending a support group meeting at BGHP or ask to be matched with a buddy. Talking to others who have gone before you in the world of chemotherapy can be very helpful. Keep in mind that not all chemotherapy affects everyone in the same way and that there are different “recipes” that clients receive for their own unique situation(s).

Check the BGHP library for information about chemotherapy (tapes, books, pamphlets). The brochure rack at BGHP has copies of Chemotherapy and You, a publication by the NCI (National Cancer Institute). It will be helpful to familiarize yourself with its contents; whether you speed read it, skim over it, or digest it slowly and completely, it can be a valuable resource, with specific sections easily identified for quick reference. **Note:** This booklet is usually given to patients by the nursing staff in Medical Oncology. It is also available online at: www.cancer.gov and can be downloaded as a PDF.

The BGHP library has several copies of Susan Love’s Breast Book, the Fully Updated and Revised Sixth Edition (2015). There is an entire chapter devoted to chemotherapy; it is called “Systemic Therapy”, and it is complete with cartoons and diagrams for better visualization of the concepts involved in this treatment modality.

TREATMENT: Getting ready

Have someone drive you to your first chemotherapy session and bring you home. If they will also be staying with you, consider someone with whom you feel comfortable, who knows you and can

anticipate your needs, a person who can “read you” and preferably knows when and when not to talk, i.e., keeping your personal information to themselves and leaving it up to you as to which people you choose to tell your “story”. After you know the “lay of the land”, you can decide if you want to drive yourself to treatment(s).

Many chemotherapy infusion centers request that those new to chemotherapy have a loved one stay with them for the duration of the first treatment in order to facilitate the development of trust and to become familiar with staff and the environment. Depending on space available, it is sometimes possible to have a private space for your first time.

Increase fluid intake the day before and the morning of chemotherapy. Eat a regular meal the morning of chemotherapy. Consider preparing flavored popsicles and ice cubes in advance. Pear nectar, apricot nectar or yogurt/juice pops may be soothing after your chemotherapy treatment. Many chemotherapy infusion centers have refrigerators and freezers and will encourage you to bring your snacks, lunches, popsicles and favorite beverages. Speaking of food, it is important to maintain a healthy diet, in spite of possible appetite changes. There are many books available that address cancer and nutrition. The National Cancer Institute (NCI) publishes Eating Hints. BGHP has some copies of Cancer Fighting Kitchen, by Rebecca Katz in its library; this book has many great recipes and tips on how to trick your taste buds if they become affected by treatment. A recipe from this book that many BGHP clients have raved about is *Magic Mineral Broth*...this is something you can delegate to someone who wants to cook for you when you want something simple, not rich or fancy.

Be prompt for your appointment. Being late (even 10-15 minutes) can adversely affect the staff in medical oncology. Be prepared with your questions before seeing the medical oncologist to make better use of the time scheduled for you. If you are having trouble getting your thoughts organized or find yourself unable to express what you need to see happen at your appointment, call us at BGHP about “consultation planning” to help you formulate and organize your questions.

Oh, and though you may arrive promptly for your appointment, you may still find yourself waiting at times. This means the oncology staff members are attending to another client’s needs. As you can imagine, situations arise when an individual needs more time than expected. Patience and understanding pay off. So take a book, Kindle, your knitting, i-Pod, i-Pad, or laptop (yes they have wireless internet) with you **or** simply enjoy the opportunity to slow down and quiet yourself. This can be a good time to listen to a visualization audiotape on chemotherapy. “People watching” or visiting with others in the waiting room are always options in situations where waiting is required. Some of the best “bonding” and “friendship building” occur during these times.

What to bring. Some clients find music or meditative messages helpful during their treatment. Books and magazines are great as long as holding them is not difficult or heavy for the hand or arm with IV in it (unless you have a “port”). Electronic devices are usually welcome. Ask about them as well as use of cell phones. Privacy, confidentiality, and respect for the quiet needs of others will likely make the use of cell phones inappropriate. You may find that headphones are helpful to screen out background noise.

You may be spending extended periods of time in the infusion center, depending on the chemotherapy “recipe” you are receiving, so bringing lunch, snacks, and your favorite beverages may increase your

comfort in this environment. A warm sweater or shawl may be helpful to regulate your own “thermostat” as well as dressing in layers. Cool cloths or a small personal fan can be helpful if you tend to run warm all the time.

Since chemotherapy is administered in a room with other people receiving similar and other therapies, you may need to find a way to create personal space for yourself...depending on the design and layout of the infusion area, a curtain or a privacy screen may be available to create that. Discuss your needs with the nurses giving your chemotherapy; they truly want to make you as comfortable as they can!

A few things that can facilitate easier placement of your IV line for chemotherapy include arriving for your chemotherapy infusion with your body warm and well hydrated. If your veins still tend to “run and hide” when the nurse approaches, a warm towel applied to the appropriate extremity can be helpful.

DURING CHEMOTHERAPY

Plan ahead for immune suppression. Be aware that within 7-10 days of receiving chemo, you are likely to be at greater risk for infection. This varies with chemotherapy medications and your own immune system. Regardless, it is best to avoid outings and places with large numbers of people, especially in confined spaces, e.g., the mall, movie or other theater venues, buses, and parties. Limit your exposure to people with suspected or known contagious illnesses and/or who have recently received live vaccines. If you haven’t already started “screening” your visitors, this is a good time to ask family members and friends to call before visiting. Even a mild sore throat, runny nose or cough can be a huge threat to your immune system at this point in the chemotherapy cycle, especially if visitors with these symptoms are children. Be particularly careful to minimize your exposure to children with a cough, runny nose, sneezing, etc. Ask for a mask when arriving for chemotherapy if you have a fever and/or a cough. And hand washing cannot be emphasized enough, for you, and those around you.

Neulasta and Neupogen are medications often given in conjunction with chemotherapy; they are both “boosters” for your white blood cells. White blood cells (WBCs) are components of your bone marrow which normally help your body to fight infection. Some chemotherapy medications can cause a decrease in white blood cells, in turn reducing one’s ability to fight infection. The down side of these drugs for some people is that they can cause bone and joint pain. If this occurs, check with your medical oncologist; Claritin and Tylenol have been helpful for others in dealing with the bone pain; ask before taking, to make sure it is okay in your situation.

Plan ahead for hair loss: If you are going to receive a chemotherapy medication that will cause your hair to fall out, do consider cutting your hair short pre-chemotherapy. There are some local salons that will cut hair at no cost pre-chemotherapy, e.g., Kalos Salon in Arcata and Judy’s Barber Shop in Eureka. Some people go wig shopping before this step so that it can be matched to their hair color and texture.

Wigs are available from American Cancer Society for free and there is a lovely variety of them in the “Breast Nest” at BGHP. Try on wigs, hats or scarves to see what they each feel like and look

like...whatever you feel comfortable wearing before losing your hair. Just know that whatever you decide to wear, it will fit differently once your hair falls out.

If you decide to cut your hair, and it's longer than 10 inches, you may be able to donate it to "Locks of Love" (toll free information line: 888-896-1588 or http://www.locks_of_love.org). This program makes wigs for children who have lost their hair. Shorter hair can still find a home. Placed outside, birds will eventually come and take it, piece by piece, for nest building materials.

Children will have an easier time accepting and adjusting to the visual changes in their mother, father or other loved one if they are allowed /encouraged to participate in the process. Talk openly with your children about the changes and try to elicit any questions they may have. Regardless of their age, you can include them in whatever decisions you make about your hair: helping to cut it, making a hair "mosaic" project with glitter glue, and playing "paint my head" with washable markers. Additional options include: picking out a wig, wearing hats, scarves or simply going "bare" and wearing more make-up and dangling earrings, as one client did. Consider creating a photo essay of your hair and scalp before your hair loss, then bald head, next picture with short hair, progressing to hair growing back all curly and full. Hair regrowth after chemotherapy can surprise you with a different color and texture than your original pre-chemotherapy hair.

Plan ahead for Scalp Care: According to Michele Knight of American Cancer Society's "Look Good, Feel Better" program, cleansing and moisturizing will help hair follicles stay in shape for future re-growth, as well as nourishing the newly exposed, and possibly tender, skin of the scalp. To avoid losing hair in large clumps, avoid curling irons, hot rollers, and blow dryers. Use a soft bristled brush so as not to scrape the scalp. Do not treat hair with bleaches, peroxide, dyes, perms, or other harsh chemicals; the scalp can be more sensitive during and immediately after treatment.

Once chemotherapy begins and before hair falls out (usually a 2-3 week time period), use a mild, pH-balanced shampoo to keep the follicles healthy. After hair loss, pamper your scalp if you like. Apply a cooling mask to your head to remove dirt and oils, followed by an alcohol-free toner to refresh the skin, then a moisturizer to stave off dryness. Protect your scalp when going outside by wearing sunscreen and a hat.

Blood Draws, Labs: You will have blood drawn on a regular basis, sometimes weekly, during chemotherapy treatment. Chemotherapy may or may not be given based on your lab results.

Coping. Try to create time for yourself and your loved ones. Some survivors plan mini-trips the weekend before their chemotherapy (when they usually feel their best). This provides for "good memories" during treatment and something to look forward to afterwards. Examples: a fishing trip, a picnic to a place you have always wanted to go, watching a sunrise or a sunset, horseback riding, a walk in the redwoods. Distractions like dancing, watching a funny movie, family game night, and massage are also helpful. Treat yourself! Weekly massages are covered by some insurance companies while undergoing treatment. BGHP has names of massage therapists with special training for or specific interest in the needs of persons with cancer. Take care of yourself!

Try to determine the dates for your last chemotherapy at the outset. Mark that date on your calendar, and begin planning for how you might like to celebrate the completion of your chemotherapy. Having such a plan will help you get through it. Remember: treatment is not a new lifestyle...it will have a beginning, middle, and an end.

Some survivors create a routine pre-and post-treatment, e.g., an outing the weekend before chemo, hydrating and meditating the day before and the morning of chemo, going shopping with a special friend or family member if feeling “high energy” immediately post- treatment (due to dexamethasone-a steroid), taking it easy and scheduling a “sleep day” the day after chemo, etc. Do whatever you can to get through diagnosis and treatment. ASK FOR HELP! Family, friends, BGHP staff and volunteers want to help!!! Allowing others to help lightens your load and gives them satisfaction as well.

Sometimes you pull the wagon and sometimes you’re in the wagon. It can be truly hard for many of us to let others do things for us. Allowing others to cook, clean, do laundry, care for children, and so forth can really help you and those who care about you. Ask a trusted, willing friend or family member to “field” phone calls, e-mails and visitors. Ask for help setting up a website like CaringBridge (www.caringbridge.org) or Lotsa Helping Hands (www.lotsahelpinghands.com) for updates and progress notes, a list of requests/needs, meal scheduling, etc. If you have a land line, use your answering machine. If you do not have one, then get one and ask for help to set it up with a message that indicates that while you are grateful for everyone’s concern and inquiries, that you are resting and someone will return their call in some kind of timely manner. You can create whatever message works for you and your family. Instruct family members not to “offer you up” for any conversations or social events/commitments you are not “up to” having/doing.....”I am not available” and “no, thank you” are perfectly appropriate responses. Give yourself permission to put a “DO NOT DISTURB” sign on the door.

Children at home. If you have children at home, arrange for a friend or family member to spend some extra “fun” time with your children. Elicit a list of fun activities or events from your children to share with those friends or family members willing to do this and with whom your children are comfortable. You may not have the energy to “entertain” your children, yet others in your “community of support” are just waiting for you to ask them to help you in any way they can...on those rough days, especially!

BGHP has some DVDs and books specific to children’s needs. Preview or ask a trusted friend or relative to preview these before you have your children watch or read to make sure the material is compatible with your philosophy. Children can be deeply affected by your treatment and may not be able to verbalize their fears and anxieties. If you notice your child or children “acting out”, regressing, or having nightmares, they may be having difficulty coping. Take a moment (or have your partner/their other parent/another trusted adult) to make time to really listen to them. One client found that reserving ten (10) minutes each day (per child) to listen worked wonders! She informed the child that this time was reserved especially for them and them alone. She found that at times they wanted to talk and at other times, they simply wanted to be held and cuddled. Hugging heals.

Children can also be very helpful, and often want to do something to make you feel better...depending on their age and capabilities, offer them some opportunities to do so.

Consider a “cancer-free zone”, 2 or 3 hours in the evening when the phone is not answered and family does not talk about cancer; this can help to normalize mealtime and bath time routines, assistance with homework and protecting family time. Remember that your loved ones may be frightened and anxious as well....give them or ask someone else to give them a specific task...it will allow them to help and to feel helpful.

Finally. You will receive a lot of information (wanted and unwanted!) about your disease process and treatments. All of this information, especially all at once, can be quite overwhelming! Read what you can, and then put what seems useful to you in a file to access at a later date. It is not possible to absorb all of this information at once and it can be emotionally frightening and scary!

Ask questions when you have them; your health care providers do not expect that you will remember everything they tell you...they realize that you are dealing with a lot; repetition is helpful!

Take one day at a time; some days it will be moment-to-moment or hour-to-hour. Go to a place of peace daily...whether it is a special and sacred space within your home, e.g., the bathtub, a favorite chair or daybed with your tea, or an outdoor space, a forest, the beach, your garden.

Talk with other survivors. Attend support group. Write in a journal. Express yourself with/in art projects. Make it up as you go...this will be uniquely your experience...do what works for you, in as much as that is possible. The only way out is through...

For more assistance in preparing for chemotherapy see article entitled Preparing for Chemotherapy, by Hester Hill Schnipper, LCSW, in her regular column called ‘Your Cancer Guide’ in the Winter 2013/2014, Volume 03, Issue 04 of “cancertoday”.

References:

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- 3) American Cancer Society website: <http://www.cancer.org>
- 4) Love, Susan M., with Lindsey, Karen & Love, Elizabeth. Susan Love’s Breast Book, 6th edition. Philadelphia: DaCapo Press, 2015.
- 5) Katz, R. Cancer Fighting Kitchen. New York, Random House, 2009.

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