

# Cancer Care Resources for Patients & Caregivers

How to help ease worry and potentially ease suffering in the midst of a whirlwind of emotions while navigating a cancer diagnosis and treatments.

## Tips for the Cancer Patient:

- Bring family, friend and recording device/notebook: You'll need backup to process what you're hearing in your visits. It's easy to forget specifics in the overwhelming amount of information and emotion. I recorded each doctor's visit on my phone or tablet in addition to coming armed with questions and taking notes. Do research and have written questions before you arrive. It's difficult to absorb the information all at once, and returning to the explanations later is very helpful.
- While undergoing chemo, use a separate bathroom whenever possible. This one was shocking to me as I'd never heard of this protocol. The meds are toxic to your family, and the bathroom will need to be sanitized after each use by the patient if sharing. Your medical team can provide greater guidance, but have gloves and cleaning supplies handy.
- Hair loss (after realizing you have to get chemo this is a big worry for many women). Start with just one or two. I was very self-conscious initially, particularly at work, but found after time I was much more comfortable being bald, particularly in the summertime.
  - Wig stores in St. Louis area
    - The Custom Wig Shoppe
      - [www.thecustomwigshoppe.com](http://www.thecustomwigshoppe.com)
      - 12076 Manchester Rd, Des Peres, MO 63131
    - Lake St. Louis Wigs and Cuts
      - [www.lakestlouiswigs.com](http://www.lakestlouiswigs.com)
      - 1305 Lake St. Louis Blvd, Lake St. Louis MO 63367
        - Several others in St Louis City, one on Grand Ave
      - TLC: an affiliate of American Cancer Society (affordable wigs and head coverings)
        - [www.tlcdirect.org](http://www.tlcdirect.org)
    - Head coverings
      - Scarves: [www.4women.com](http://www.4women.com) has a wide variety of cute and comfortable scarves to choose from; I personally loved these when I didn't want to wear a wig.
      - Silly hats: have at least 1 to help you laugh; especially great if you have kids to help them cope in a positive way
    - Enroll in the "Look Good, Feel Better" program, available through the Siteman Cancer Centers and other organizations. <http://lookgoodfeelbetter.org/> Here you will learn how to manage wigs and some programs offer makeovers and tips for caring for scalp, hair and skin changes during treatment.
    - Itchy scalp
      - Witch hazel: apply on cotton ball and rub on scalp

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- Cleaning for a Reason (Free Housecleaning During Treatment):  
<https://cleaningforareason.org/patients-2/learn-more>
  - Several organizations contribute their services for people in need. Just google “free housecleaning during cancer treatment” and the options will come up.
- Bone pain from Neulasta or Neupogen
  - This was as bad if not worse than side effects from chemo; let patients know how this can feel so they’re prepared. Some days are difficult to get out of bed and patients may need assistance.
  - Loratadine (Claritin) taken the day before your shot and for 4-5 days afterwards really improved the pain.
  - Getting the injection in your abdomen reportedly doesn’t cause as much pain as getting it in your arm; after getting my first shot in the arm and suffering through horrible bone pain and headache, I got subsequent shots in my belly. Don’t know if it was this or taking Claritin, but the pain was significantly better with the rest of the shots.
  - Heating pad for achy joints
- Dry mouth/Nose
  - Drink plenty of water
    - Chewing gum – Trident, Biotene
  - Lemon drops
  - Ayr Saline Nasal Gel for dry or bloody nose – can order on Amazon
  - Biotene mouth rinse (REALLY helped)
  - Good mouth care, teeth and tongue brushing
- Nutrition: important to maintain good nutrition for healing after surgery and for body to deal with chemotherapy
  - Mouth can get sore from chemo so try soft foods that are good protein sources
    - Greek yogurt, applesauce, cottage cheese
    - Eggs, mashed potatoes, quinoa
    - Peanut butter
    - Protein powder smoothies or Ensure protein drink
    - Canned tuna
  - Fiber: GI tract has its ups and downs from constipation to diarrhea so maintaining adequate fiber can help
    - whole grain breads and cereals
    - fruits and vegetables
  - Taste changes: foods don’t taste as expected or even good but must eat for nutrition; taste comes back after time.
- Constipation due to treatments or pain meds
  - Stool softener/laxative (docusate/senna): constipation may hit day after chemo so can take this night after chemo to help prevent; may need to take for several days.
  - If chronic, try magnesium citrate, an over-the-counter liquid. Consult pharmacist with any questions. Recommend trying smaller amounts and adding as necessary.

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- Diarrhea: this could happen after several days of constipation; stay hydrated with water and Gatorade, and loperamide (Imodium) helped if became excessive
- Skin/nail reactions
  - Rash/redness/skin discoloration
    - Hydrocortisone cream
  - Dry skin
    - Keep skin moisturized with creams and lotions. Try dermatologist recommended CeraVe Healing Ointment for radiation burns and dry skin
    - Don't take too hot of showers – can inhibit circulation and promote lymphedema
    - Rubber gloves or non-latex gloves for around the house: skin is very sensitive to any cleaning products and even to dishwashing soap
  - Nails
    - May see changes in nail appearance with white lines or may start to come away from nailbed
    - I tried painting my nails to try to prevent, and if not prevented to cover the appearance
- Infusion days
  - Come prepared to sit awhile
    - Blanket if you'd like your own piece of coziness from home (infusion center has warm blankets usually available)
    - Music to relax
    - Headphones for TV
    - Books/magazines
    - Laptop
    - Drink/snacks
  - Ask questions
    - If you don't feel right during the treatment, immediately ask a nurse, they may need to slow down or stop the infusion
    - Ask for written information on the drugs you're receiving and any special instructions i.e getting Cytoxan should be told to drink plenty of water for the following several days
- Take time to REST and treat yourself kindly
  - Get adequate sleep
  - Take naps
  - Give yourself something to look forward to after chemo days i.e movie, massage, favorite restaurant, jewelry
  - Get a puppy
- Exercise
  - Improves body, mind and spirit. Be in nature whenever possible.
  - Even just a walk is helpful on your weaker days – 30 minutes a day when possible
- Alternative/Additional therapies
  - Massage, reflexology, acupuncture, Reiki, Meditation, Gratitude Journal

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- Don't suffer in silence
  - Ask medical team for help when you need it and take medicines to help alleviate symptoms
- Reading recommendation received from a physician who was also going through treatment at the time that really impacted my perspective forever: Love, Medicine, and Miracles by Bernie Siegel, M.D. Based on this I would visualize radiation treatment as sunshine that helped grow a beautiful garden in me.

## ONLINE / RESOURCES for PATIENT & CAREGIVER:

- **Cancer Support Community:** <https://www.cancersupportcommunity.org/>
  - Comprehensive website offering medical and community resources for patients and caregivers
  - Support resources for: Nutrition & recipes, free transportation and housing, financial options, physical, emotional and social support, online discussion boards and expert medical advice, clinical trial information, cancer registry and Communication boards for family and friends – can be managed by caregivers as the information provider. Meal plans: <https://thebreastcancercharities.org/meal-planning-eat-week/>
  - Communication board MyLifeLine to communicate treatment progress to family and friends
- **Caring Bridge Personal Health Board** - Communication board: <https://www.caringbridge.org/> to communicate treatment progress to family and friends.
- **Siteman Cancer Center** (6 Metro-East Locations): <https://siteman.wustl.edu/> Website appears to focus mainly on medical treatment, but will offer nutrition, counseling and other services
- **Mercy Medical Center St. Louis** (3 St. Louis Locations): <https://www.mercy.net/service/cancer-rehabilitation-and-therapy/> A phenomenal and comprehensive website offering information on medical, physical and emotional support before, during and after treatment.
- **The TUTUproject:** Just about every breast cancer resource available: <https://thetutuproject.com/breast-cancer-resources/>
- Medical team: needs to discuss with patient more than just the actual treatment, but include the patient in the discussion to get their input as well as assess their coping ability. Educate them for what to expect from infusion room to side effects.
- Online resources: many available but one I found most useful, especially the discussion boards [www.breastcancer.org](http://www.breastcancer.org)
- Susan B. Komen Race for the Cure: <https://www5.komen.org/>