

Living Life During Cancer Treatment



Ideas, Tips and Suggestions
For Cancer Patients By Cancer Patients

Brought to you by NW Surgical Oncology, PC

For Latients, From Latients...

Cancer is scary and confusing to both the person diagnosed as well as the people who love them. Living with and fighting against cancer often requires a whole new set of rules and ways of doing things that are different than regular 'civilian' life.

For this reason, we collected ideas and suggestions from former cancer patients and caregivers to help those navigating the muddy water of cancer treatment.

Please keep in mind, however, that the suggestions contained in this booklet do not substitute for advice from your doctor or medical team. If you are experiencing physical or emotional concerns while in treatment, please contact your doctor for further help and support.

We hope that this collection of tips and suggestions are of help to you. If, in your own journey, you made discoveries not listed here, let us know. We may be able to include them in updated issues of this booklet. (Please send your suggestions to info@nwsurgicaloncology.com)

Here's to your health and successful treatment!

--Dr. Katherine Morris and the team at NW Surgical Oncology

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No, You're Not Losing Your Mind (Even if it Seems Like it)

Thoughts on Emotional Health

Cancer comes with a whole set of roller coaster emotions. Remember this when you experience your own ups and downs.

Keep a journal to help process your emotions.

Take short walks--it's amazing how much clarity a walk can bring to your situation.

Use humor to cope (it helps others cope, too).

Choose your attitude. With cancer so much is out of your control, but you can choose how you will deal with it.

Let your family and friends know how they can help you. Many of them will want to help but don't know what to do.

Join a support group to talk to others going through similar struggles that you can't talk to your loved ones about.

Pamper yourself! (If you love music, listen to your favorite artist, if you love the ocean, put a favorite picture near your most comfortable Breathe In Breathe Out

When I was going through cancer treatment, I felt like a failure because 1 wasn't able to do many of the things 1 was used to doing.

During that time, one of my friends gave me this advice: "lust breathe in and breathe out. That's all. You don't have to worry about the rest."

That simple wisdom is what I needed to give myself permission to adjust my expectations for a season while I battled cancer.

> -- Kathrun, Cancer Survivor

Saying Goodbye to Your Hair

Thoughts on Hair Loss

Adopt a positive attitude about losing your hair. Use it as an excuse to do something wild and crazy with it before it falls out. (Even if you end up hating it, you won't be stuck with it very long.)

Cut it short or shave it off (with an electric shaver) before it falls out.

Let a friend give you a head shaving party and make an event of it. It's empowering to control when your hair comes off.

Buy a wig while you still have hair and wear it around a bit to get used to it before you actually need it (the wig can be made to closely match your own hair, if you want). If you can't afford a wig, the American Cancer Society can help you get one.

If your hair starts growing in between treatments, re-shave it with an electric shaver the night before chemo in order to avoid 'shedding'. (It also sometimes works to use a lint brush the same way.)

I was definitely not excited about the prospect of losing my hair. I'd never been crazy about 'bald' anyway, and I certainly didn't want to see it on me. In order to lessen the pain, I had a head shaving party and invited my family and friends to come. In the end, being bald wasn't as bad as I thought it would be, and a big added bonus was that my hair grew back in curly—just like I'd always wanted!

--Grace. Cancer Survivor

Advice for Cancer Patients You Can Ask For What You Need (Really, you can!) Working With Your Medical Team

Ask any questions you have and don't be afraid to keep asking until you understand the answers.

Don't be afraid to ask for a second opinion. It won't hurt your doctor's feelings.

Keep a current list of medications with you (with time taken, dosage amounts and what it's for) when visiting your doctor.

Bring a support person with you to your appointment to take notes.

If your doctor doesn't mind, consider bringing a tape recorder with you to your appointments. Ask them first.

Learn as much as you can about the disease. Ask if your doctor knows of any resources that pertain specifically to your type of cancer.

If the first treatment goes poorly, don't resign yourself to more of the same. Keep asking for and trying new techniques, medicines, liquids, schedules, etc. until you get a combination that works for you.

Please keep in mind that treatment may go poorly at first, but it sometimes gets better as you continue.

Surgery and Chemotherapy:

Tips for Making it Through

If you're having any abdominal surgery, get some larger sized underwear and pants (and other things you wear around your waist) to decrease discomfort while you're healing.

Have someone drive you to and from your first doctor appointments, before and after surgery, and to the first one or two chemotherapy sessions. Even if you feel like you can go alone, you'll appreciate the support and distraction a friend can provide.

For surgery on 'underwear line' places, men's boxers (even for women) work well to keep the pressure off the incision.

Take reading material, knitting, or some other pastime with you to your chemotherapy to help pass the time and keep your mind occupied.

Make sure you have some sort of electrolyte drink (Gatorade, Powerade, Pedialyte, etc.) available after surgery and during chemo.

We installed handicap bars (they're inexpensive and can be removed) to the bathtub and toilet area to help with safe safety when mom came to visit. They turned out to be very helpful for my chemo and post-surgery times. I wouldn't have thought of it for cancer treatment, but it ended up being very useful and I was thankful that we had them.

-Phyllis, Cancer Survivor

When Your Brain Goes Missing (You will eventually find it again)

Thoughts on Dealing with 'Chemo Brain'

Write things down. Don't assume you will remember, you might not.

Keep dates on a calendar to help you keep appointments straight.

Use a pill box and/or medicine charts to help you (and others) keep track of your medication.

Have someone come with you to appointments to take notes and ask questions for/with you.

Give yourself a break. Recognize that chemo brain is sometimes a side effect of chemo.

Remind yourself that this is temporary. Your brain will return!

After my bilateral mastectomy I was such a mess of physical and emotional pain. I felt like an alien with a possible death sentence, no longer part of humanity. I needed something warm and human and personal that took no work to grasp. My daughter brought me 'Chicken Soup for the Breast Cancer Patient's Heart'. I drew comfort from the wise and humorous stories that presupposed God was working. They were told by people who went through cancer and were thriving now. I needed that.

-- Robilyn, Cancer Survivor

Advice for Cancer Patients When Your Stomach Rebels

(And you can't convince it to behave)
Thoughts on Coping with Nausea

Don't wait until you feel sick to take your antinausea medicine. You don't have to play it tough.

Eat foods that are easy on your stomach such as clear broth, clear soda, tea, water, crackers, pasta, oatmeal, rice, potatoes, gelatin, Popsicles, yogurt and bananas (and stay away from spicy, sweet, or greasy foods).

Try travel bands for motion sickness.

Drink small amouts of oat milk to soothe the stomach.

Drink ginger tea or eat ginger candy to help settle nausea.

Let your food cool before eating it.

If you can, have someone else cook for you.

Drink liquid yogurts--they're small, easy to drink and contain protein.

If your nausea persists despite your efforts to control it, ask your doctor about getting extra IV fluids for a day or two after treatment.

Don't ask what the patient would like to eat, or even if they would like to eat. Just cook it (away from the patient and without letting them smell it) and deliver it to them.

The nausea makes everything sound bad, but without pre-smelling and pre-thought, the appetite is better and they will be able to eat more.

---Bette, sister of cancer patient

Remembering to Eat (& Drink)

(Whether you feel like it or not)

Getting the Nourishment You Need

Even if you're not hungry, set a goal for yourself to eat even a few bites at every meal.

If food begins to taste like metal, eat with plastic utensils.

Don't drink too much before meal times so that you don't get full before you even start eating.

Graze throughout the day instead of eating bigger meals. If you find yourself filling up too quickly, consider trying to eat every two hours during the day instead.

Plan your meals--what you will eat and when--so that you don't have to make last minute decisions or worse, decide NOT to eat because you don't want to make any decisions at all.

As for eating...that was always a problem. We finally made a game out of this and got a sheriff badge and began "policing". We even used siren sounds etc. It worked to get the water down and more food too.

-- CL Montgomery, Daughter of cancer patient

More Tips on Eating & Drinking

Set a timer for 30-45 minutes to remind yourself to drink fluids. Even if you only drink half a cup, if you do it regularly, you'll get what you need.

If you're struggling with your caloric intake, consider drinking liquids with calories instead of just water.

Drink a shake made with Ensure, fresh fruit and milk. It tastes good and gets more liquid and other good stuff down.

Try juicing your own juices for healthy alternatives (or have someone do it for you.)

When people ask what they can do for you, suggest they prepare small, single serving foods that you can put in the freezer and re-heat for easy meals.

When my sister, who is single and lives alone, was going through chemo, she struggled with eating. Not being a cook myself, I didn't know how to help her.

Finally, I got the idea of ordering out from a local resturant once or twice a week. I'd order a kids meal for her, pick it up, and bring it to her house.

We'd have dinner together and she'd have enough leftovers for another meal for the next day, It worked great,

--Shelly, Sister of cancer patient

Advice for Cancer Patients Napping Never Felt So Good!

(And why does everything take so much effort?)

Dealing with Fatigue

Be kind to yourself.

Learn to pace yourself. You're probably not going to be running any marathons while you're in treatment. But that's okay. You're running a different kind of race and it takes a lot of energy.

Do LESS.

Let others help you (and be specific about what they can do to help). Learn to ask for help.

Do the important things first and let the other things slide.

Eat and drink regularly.

Establish routines that help you relax.

Don't expect too much from yourself immediately following treatment. If possible, clear your schedule and get as much rest as possible.

Think of this as a journey. Lots of ups and downs. We rejoiced with Hom during the ups and cried with her during the downs. It is YERY important to have a good support team around the person struggling.

That makes all the difference to both the cancer patient and the immediate family.

— Chris, Daughter of cancer patient

tare Cancer, Will Travel

(Just because I'm sick do I have to stay home?)

Tips for Traveling with Cancer

Don't be afraid to request extra assistance when traveling (ie skycap, help boarding, etc.)

If your carry-ons are flagged for checking by TSA, request they change their rubber gloves before searching your bags. This will keep extra germs (from other previously searched suitcases) from entering yours.

Wear a face mask and bring hand sanitizer with you.

Avoid crowded places when possible.

When the person with cancer gets tired of being cooped up within the same walls for days on end-drive them to their favorite spot for a change of scenery. For my dad, this was the beach. It lifted his spirits just to get out.

-- Shelley, Daughter of cancer patient

Advice for Caregivers The Sometimes Thankless Job (But it has life long rewards!)

Ways to Help the Cancer Patient

Do groundwork/paperwork for medical/prescription insurance and forms. The paperwork can be overwhelming to the healthy, let alone the sick.

Run errands for the patient.

Remind the patient to eat and drink.

Feed them, even if they're not hungry.

Be willing to spend the night in the hospital if that is comforting to the patient.

Remind them about their pain medication so they can stay on top of their pain management.

Prepare meals for them.

Screen people who want to come and visit.

Protect them from unhelpful or counterproductive family and friends.

Touch them--touch is very healing.

Encouragement, encouragement, encouragement is another key. Never, ever, give up!! Lots of cards are always welcome as well as phone calls if the person can get to the phone.

Chris, Daughter of cancer patient

Encouragement is a k

More Ways to Help the Cancer Patient

Be sensitive to their needs (if noise bothers them, help keep things quiet, etc.)

Take short walks with them. Encourage them to walk even if they don't feel like it.

Sometimes just being with them, even if they're sleeping, is a comfort to them.

Keep in mind that patients don't usually need entertainment. Mostly they need rest and quiet. You don't have to be 'on' all the time.

Be careful using scented smells (lotions, perfume, soaps, etc.). Sometimes cancer patients are ultra sensitive to smells after treatment.

Be prepared for some raw emotions from the patient. Give space for venting, if needed. Don't take it personally and don't panic from the severity of the emotions.

Remember that you don't have to solve any problems. Often, just listening is enough.

Ask if they would like your advice before offering any.

Many Hands Make Light(er) Work

(You don't have to carry it alone)

Allowing Others to Help

Make a list of helpful things others can do for the patient. Have it ready when people ask what they can do.

Ask for help. Many people want to help but don't know what to do, or are waiting to be asked. Take the initiative.

Small, individual meals prepared and frozen can be helpful to the patient and an easy task for others to do.

If someone is going to come over to visit or help, remind them not to wear strong scents.

Remember that not everyone is able to be around the patient. Illness can trigger all kinds of emotions and unresolved issues for people. Try not to take it personally or resent those that 'disappear' during this time. Be thankful for those that can and want to help and gladly take what they can offer.

One of the hardest things about being a caretaker is realizing that you can't fix everything or change the situation. You're human and have limitations and you get tired. It's very hard to watch someone you love suffer and realize you can't be the Savior.

--Roseanne, Daugher of cancer patient

Signs of the Times (It's okay to acknowledge your own needs)

Paying Attention to the Stress Warning Signs

The number one thing caretakers stressed was this: YOU NEED HELP. YOU CAN'T DO IT ALONE.

If you don't have a support system around you, gather one. Taking care of someone who is very sick requires a team.

Pay attention to yourself during your time of caretaking. Watch for signs of stress. Talk to someone if you see some of the following issues in your life:

- Feelings of guilt
 Feelings of anger
- 3. Increased anxiety
- 4. Inability to concentrate
- 5. Greater than normal fatigue
- 6. Depression
- 7. Weight loss or weight gain

Although any (or even all) of these feelings may be present as a caretaker, if they're overwhelming, you need to get help.

As a caretaker you need to get away from the situation from time to time. Get comeone to take care of the patient, or even to just be there while they are sleeping, and then go out to a movie for a few hours and forget about what's going on for a while.

There can be quilt feelings that come with getting away, but push them out of the way because you need to be revived in order to help those who need you.

-Susan, Daughter of cancer patient

When Your Emotions Hit a Snag

(You can't always be a rock)

Dealing with Your OWN Ups and Downs

Realize you can't do it alone and accept help from others (this does NOT mean you're weak, it means you're smart).

Let others know how they can help. Many are willing, but don't know what to do.

Recognize the idea "It's all up to me" is a lie. Ask for what you need, don't wait for someone to offer.

Guilt is a common emotion amongst caregivers. You don't have to be all things at all times to your loved one. Know your limitations.

Don't be afraid to talk honestly with the patient (and allow them to talk honestly in return).

LET GO of mistakes. You're human.

Don't be afraid to cry or get angry. It's okay to express your feelings.

Try to understand the patient's feelings, but don't take them personally.

The "Sandwich" Person (Juggling life between patient and doctor)

Working With the Medical Team

Ask questions and take notes.

Keep a current list of patient's medications (with times and dosage) with you.

Learn as much as you can about the disease.

Learn if there are different options and ask why one is recommended over the others.

Be an advocate for the patient. Don't be afraid to speak up.

Be honest with the doctor/medical team.

Stay pleasant even when it's hard. Remember that the medical team is both human and on your (and the patient"s) side. They want to work with you.

Make friends with the nurses. They're an excellent source of knowledge, help and advocacy.

After our first round of chemotherapy, one of the nurses sat down with us and explained in detail what to expect which was a great help to us as we'd never faced cancer before. Later, another nurse (who had survived cancer herself) became a wonderful advocate for us in making sure we got all the services we needed and didn't know to ask for. When I shared my head in support, the nurses were there taking before/after pictures and encouraging us along. They were a huge help and support to us all along the way. I can't thank them enough.

— Linda, Sister of cancer patient

Advice for Family & Friends What Do We Do?

(Yes, you have a vital role)

Ways to Help Both Patient & Caregiver

Everyone is focused on the patient, but don't forget to check in with the caregiver as well. Caregiving can be a very hard and very draining.

Offer your help without waiting to be asked. Most often help is welcomed by patients/caregivers who are overwhelmed, don't know how to ask, don't want to burden others, or aren't sure who to ask for help.

Send cards and notes. They take less energy (for the patient) than phone calls and visits and let them know they haven't been forgotten.

Check first about sending flowers. Sometimes patients have a super strong sense of smell and can't tolerate strong scents. Also, some patients aren't allowed flowers because they transmit bacteria.

I made a quilt for Mom after her first surgery before she began cancer treatments. It was very bright and cheery and she took it to the hospital each time she was admitted for something. I'm not sure why, but she wanted it with her.

— Crystal, daughter of cancer patient

Don't wear strong perfume when visiting because the scent can be overwhelming to the patient.

When you offer help, offer in general, and follow up with specific things you can do such as bringing over a meal once a week, running errands, cleaning the house, etc.

What Patients Wished You Understood

Cancer Patient Pet Peere List

Please don't tell me WHY I have cancer (or ask me why I have it either).

Please don't offer your advice unless I ask for it.

Please don't tell me cancer HORROR stories. I don't want to know about people that had a hard time or died from cancer.

Please keep your sense of humor.

Please allow me to use my sense of humor and don't be offended when I do, even if it seems macabre.

Please allow me to be honest with how I'm feeling and what I'm thinking.

Please don't treat me like I can't make any decisions.

Please support me in my choices for treatment even if you would make different ones.

Please don't say, "Oh, you'll be fine" if you have no idea what it looks and feels like to be in my shoes.

Please don't treat me like I"m damaged or tainted. Don't be afraid to be around me; you can't catch cancer from me.

Please don't feel sorry for me.

What Patients Wished You Understood

Cancer Patient Pet Peere List, cont.

Please ask me if you want to know how I am. You don't have to ask others. I'm still capable of answering questions myself.

Please don't disappear because you don't know how to act around me. I'm still the same person, I'm just fighting a disease.

Please do not tell me that I'm sick because I lack faith!

Please do not tell me I'm sick because I ate meat, like chocolate, drank wine, didn't take care of myself, or anything else. The point is, I'm already sick and there's nothing I can do about the past.

Please don't stop touching me. You aren't going to catch cancer by hugging me.

Please don't say you're doing to do something radical (like shave your head in support of me) unless you really are. You don't have to be a hero for me.

Please don't talk to my doctor or medical team like I'm not in the room. I'm not dead yet!

What Caregivers Wished You Understood

Caregirer Patient Pet Peere List

To Patients:

Please remember that although cancer is the focus of your life right now, I have other responsibilities that I'm trying to balance, too.

Please understand that I can't do everything for you all the time. Sometimes I need a break. That doesn't mean I care less, it just means that I'm trying to take care of myself.

Please don't take it out on me. It's not my fault you're sick/weak/tired/in pain/struggling with insurance issues/scared, etc. I will listen to you when you need an ear, but don't blame me or treat me like it's my fault.

To Others:

Please understand that I'm doing the best I can and am still human. Don't criticize me or tell me how to do it better.

Please volunteer help so that I don't have to try to track it down myself.

Please know that even though the focus of our energies are on the patient, I have needs/fears/feelings too. Don't judge me; allow me to process my emotions without your condemnation.

My husband had cancer and someone told me that whatever you husband wanted to do, do it—whether it was going on a trip or shopping or just going for a ride or sitting and talking. Those moments are not only precious to the cancer patient, but also to the caregiver for years to come.

- Doris, wife of cancer patient



A special thank you to all the patients and caregivers who made this book possible.

Think of cancer as a chronic illness instead of a terminal illness.
--Millie, Long Time Cancer Survivor

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