



Tips and Tricks from Ovarian Cancer Survivors

We want to help you live your best life throughout your ovarian cancer journey—from diagnosis to post-treatment. This guide includes tips and tricks from a small group of ovarian cancer survivors in the MOCA community.

The information provided should not be considered a substitute for the opinion of a qualified health care provider. MOCA does not recommend or guarantee any product mentioned. Please use this information to assist you in obtaining further information and in making your own health care decisions.

Recently diagnosed?

- Make sure you are being treated by a gynecologic oncologist, a specialist in the treatment of gynecologic cancers.
- Ask questions. Be your own advocate. Write down your questions and consider sharing them with your doctor before your appointment.
- Remember, you decide with whom to share the news of your diagnosis. Some people set up a <u>CaringBridge</u> site, which can help disseminate news about your cancer journey. You can limit who has access, or leave it open for anyone to see. Share updates if you are comfortable. Sending group emails and texting is okay, too.
- lt may be difficult, but don't be afraid to ask friends and family for help.
- Sometimes, friends and family want to offer support, but they may not know what to do. Be prepared when they ask how they can help—and be honest. Think about what you might need from the store or how they could help around the house. Could they take you to your appointments, vacuum, mow your lawn, or just come over and visit?
- ldentify and develop a core group of "helpers", including friends and relatives you can rely on.
- Have someone set up a <u>Meal Train</u> (online resource) for delivery of meals, or coordinate delivery with another service.
- It's helpful if a friend or family member can join you at all doctors' appointments and take notes for you. If your supporter can't travel, ask them to call in by phone. Having someone you trust to listen to your health care team, take notes and ask questions—is invaluable.
- Take advantage of the support that may be offered to you including social workers, therapists, pastors, spiritual leaders and MOCA Support Groups.
- Know that treatments have advanced greatly, especially in the last 10 years. Survival statistics may not be relevant.

Receiving chemotherapy?

- Ask your health care provider if you can have someone stay with you during your chemo treatments.
- Most treatment centers have snacks, beverages and warm blankets available. If you want something specific, consider bringing your own snacks.
- Here are some items to consider bringing to chemotherapy: something to read, headphones for listening to music, audio books or a podcast, lap blanket and eye drops in case your eyes get dry. Many health care facilities also have blankets to offer if you are cold.
- Stay hydrated before, during and after chemo. Water might not taste good, but try to drink it.
- Your doctor may talk with you about putting in a chest port for treatment and blood draws. Make sure you understand the risks and benefits. If you don't have one put in, each time you go in for treatment you will need to have an IV placed.
- Many survivors have found that chemo nurses are a wealth of knowledge! Make sure to ask them questions and be open about any side effects you are experiencing.
- Walk every day if you can! Do what is comfortable for you, but moving may help you feel better. Whether you walk a block or a couple of miles, it makes a difference. Gentle exercise may help build energy.
- You may have a variety of medications to be managed, so it helps to set up a tracking sheet to ensure you are taking them at the right time.
- You will probably feel pretty good for 1-2 days after treatments. By day 3, you might start feeling side effects. Before starting chemo, ask your treatment team for guidance on how to manage post-treatment side effects.
- If you start to feel sick or if you are not sure if what you are feeling is normal, make sure to ask your nurse or another health care provider. Often, your care facility will have a special phone number for chemo patients to call for advice.
- It's great if you can have someone at your home or stop by to visit post-chemo if you aren't feeling well.

Receiving chemotherapy?

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- Talk to your health care provider about preventing neuropathy. This side effect often impacts the hands and feet and causes numbness, pain and weakness.
- Putting ice packs on your feet and hands during Carbo/Taxol treatment may help prevent nerve damage. You may also want to use chemo ice gloves and socks. These items can be purchased on Amazon or from other vendors. Start icing 15 minutes before treatment, throughout treatment and for 15 minutes after treatment.
- Stay hydrated before, during and after chemo. Water might not taste good, but try to drink it.
- Wearing socks/footies and gloves can help make the cold more bearable.
- Ask your provider about taking an antihistamine such as Claritin-D to help prevent neuropathy. Be sure to ask about the proper dosage.
- Ask your health care team about taking vitamin B and L-Glutamine to help prevent neuropathy. Make sure to ask about the recommended dosage.

Preparing for surgery?

- Everyone is different, but you should expect to spend 3-4 nights in the hospital following surgery. Ask your health care team about what to expect.
- Pack extra underwear and consider buying socks with grips on the bottom. Nurses will have you try to get up and out of bed soon after surgery. Having your own comfortable pair of socks will help your feet feel better on the cold floor.
- Consider packing loose-fitting sweatpants to wear for the ride home after surgery. Wearing loose, casual dresses, elastic waist pants and tunics for the first few weeks after surgery is often helpful. Slip-on shoes will also be helpful.

Preparing for surgery?

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- After surgery, you may be given an abdominal band to help support the abdominal muscles after surgery. Many survivors find the band to be very helpful. Consider asking for additional bands before you are discharged or order them online because it's helpful to have more than one.
- Following surgery, you will be given shots of blood thinner in the abdominal area. Many times, it's prescribed for 21 days. You should be prepared to give yourself the shots or have someone available daily to administer.
- Set up a place in your home to relax that isn't your bed, such as a couch or comfortable chair. Navigating stairs can be difficult soon after surgery. Try to find a spot to rest on the main floor.
- When you first get home, you won't have the energy to deal with many household activities. Think about making plans for help with housekeeping, shopping, laundry and cooking. After a couple weeks, you will feel well enough to start doing some of these tasks. Don't overdo it.
- Typical bath sheets may be heavy and hard to handle, so consider having smaller bath towels you can use comfortably.
- Having extra pillows to prop yourself up— in your bed or couch will be helpful. One survivor found a reading pillow with arms to be helpful.
- If your bed is high, you may want to have a step stool to help you get into bed and not strain yourself.
- Ask if your surgeon will take tissue samples for tumor testing. Tumor testing is an important tool to determine treatments along with providing information to your family regarding the risk of developing ovarian cancer or other related cancers.
- In rare cases, your surgeon may have performed an ileostomy or colostomy due to the spread of cancer. Recovering from these operations may be challenging. You may find helpful information at <u>ostomy.org</u>.

Concerns about diet and nutrition?

- Explore what types of food you tolerate best and make you feel good.
- Make and freeze meals ahead of time for when you don't feel like cooking. Or, ask others to help by making you meals.
- Try to eat what and when you can. Certain foods might not taste good, but remember—food is medicine, so find the foods you can eat.
- Talk to your treatment team about what foods are okay to eat and those to avoid.
- One survivor shared that she felt better if she had protein for breakfast. Some high protein foods survivors recommend include: scrambled eggs, egg salad, peanut butter, protein drinks, clear protein drinks (as a substitute for water), yogurt or yogurt drinks, pudding/tapioca and cheese sticks.
- Consider freezing your morning protein shake and making popsicles. Try combining your favorite protein powder, spinach or kale, half a banana, half a beet, half an avocado, frozen berries, Greek yogurt and some oat milk or liquid. Blend and freeze!
- Think about incorporating fermented foods into your diet (kefir, raw sauerkraut, etc.) to help maintain your healthy gut bacteria.
- For additional fiber in your diet, you may want to try chia seeds. Look for recipes that use chia seeds to thicken smoothies and liquids. Prunes, prune juice and wheat cereals also include fiber. Hemp hearts or seeds can be sprinkled on cereal to add more fiber and nutrients.
- Drink as much fluid as you can every day.
- You may want to consider keeping a "food diary" and writing down what you are eating in a day. Survivors have found this helps to provide a sense of control.
- You may not want to eat any of your favorite foods while you are receiving treatment. Some survivors have shared that you may not want to eat them after treatment if you have a bad experience.

Concerns about diet and nutrition?

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Interested in learning more about nutrition during cancer?

Here is a list of books recommended by our survivors.

- The Cancer Fighting Kitchen: Nourishing Big-Flavor Recipes for Cancer Treatment and Recovery" by Rebecca Katz.
- "Cookbook- Eating Well Through Cancer" by Holly Glegg and Gerald Miletello.
- "Cured: Strengthen your Immune System and Heal Your Life" by Jeffrey Rediger, MD.
- "Wake up Grateful" by Kristi Nelson

Exercise/Movement

- Getting exercise and being active are important for healing, along with getting a good night's sleep. Don't exercise more than your health care provider recommends after surgery.
- Keep moving as much as possible. When you do have energy, be active. You might just be able to walk around your house at first. Eventually you may be able to take longer walks.
- Don't be afraid to invest in equipment that will allow you to be active at home, especially as you start treatment. For example, some survivors have benefited from purchasing e-bikes (electric bikes) so they can enjoy the outdoors, even when they are not feeling well.
- Regular walking assists in your ability to maintain balance.
- Find a trainer who will encourage you to get up and move. Gentle exercise may help build energy.
- Dance! It can be fun and energizing—and it's a great whole-body exercise.
- Light stretching and yoga may also help during recovery.

You are not alone!

- Pay attention to your mental health. Cancer is a lot of work. If you have someone to talk to about what you're going through, it can help you immensely.
- Consider seeing a therapist. If you're feeling down, anxious or depressed, know that you are not alone. Get some help from a trained medical professional.
- Don't expect to be able to do what you used to do. It's okay. This is temporary.
- It's normal if every ache or pain triggers anxiety. Don't panic. Keep track of these symptoms—and if you see a pattern or they don't go away after a couple weeks, let your oncologist know. A palliative care doctor may also provide useful information.
- Regular meditation can be helpful. <u>Grateful Living</u> is a website which sends an inspirational quote each day and includes online courses.
- The <u>Calm</u> website has been helpful in reducing anxiety among survivors. Calm offers a 10-minute daily meditation and exercises.
- Listening to music may be helpful. Make yourself a playlist of songs you love.

Post Treatment

- When you finish treatment, you may feel depressed or anxious. You just spent months focused on actively doing things to deal with the cancer. Now, suddenly it feels like you aren't doing anything. There are things you can do! Focus on being active, eating healthy and planning activities you can do once you are ready.
- A great resource for free personal training sessions is <u>Survival2Strength</u>. Survival2Strength offers free sessions to cancer survivors.

Post Treatment

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- Your health care team might talk with you about going on a maintenance treatment such as a PARP inhibitor. Learn about the side effects. If you experience side effects, talk to your doctor about whether a different dosage of medication may be effective.
- You will continue to get your CA-125 tested. Every follow-up visit to your oncologist could trigger anxiety. This is normal. Know that after time, the anxiety lessens. It may never go away, but you will find you won't be as focused on it.