



Ovarian Cancer Resource Guide for women with recurrent disease





About the National Ovarian Cancer Coalition (NOCC)

Our mission is to raise awareness and promote education about ovarian cancer. The Coalition is committed to improving the survival rate and quality of life for women with ovarian cancer.

Since its inception, NOCC has built a highly-respected national presence through its nationwide network of thousands of volunteers. It has established itself as an important advocate for patients and families struggling with a diagnosis of ovarian cancer.

NOCC's network of Chapters fuels ovarian cancer awareness on a local level and is the heart and soul of the organization's structure. Participation in a local Chapter is a great way for women to stay aware and make a difference.

NOCC provides valuable up-to-date information through its toll-free ovarian cancer helpline, 1-888-OVARIAN, and a comprehensive award-winning website, *www.ovarian.org*.



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Facing Recurrent Ovarian Cancer

Learning that you have recurrent ovarian cancer brings on many new fears, concerns and questions. You may feel similar to how you felt when you were newly diagnosed, however, some women say they feel more uncertain following a recurrence.

The National Ovarian Cancer Coalition hopes this booklet will help you to make informed decisions about your treatment for recurrence and be proactive in managing your health.

You've been down this road before – but this is an entirely new journey. We encourage you to draw on the strength that helped you through the first time.

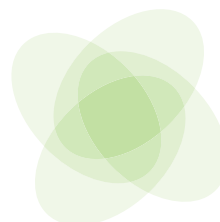
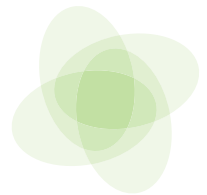
We know this is a challenging time for you and your family. Try to stay positive, empower yourself with information, channel your strength, and most of all, remain hopeful.

This booklet is not meant to take the place of direct communication with your treatment team and with others who have been through similar situations. It is another tool for you to use as you face your recurrence. The more you know, the easier it will be to make decisions that are best for you.

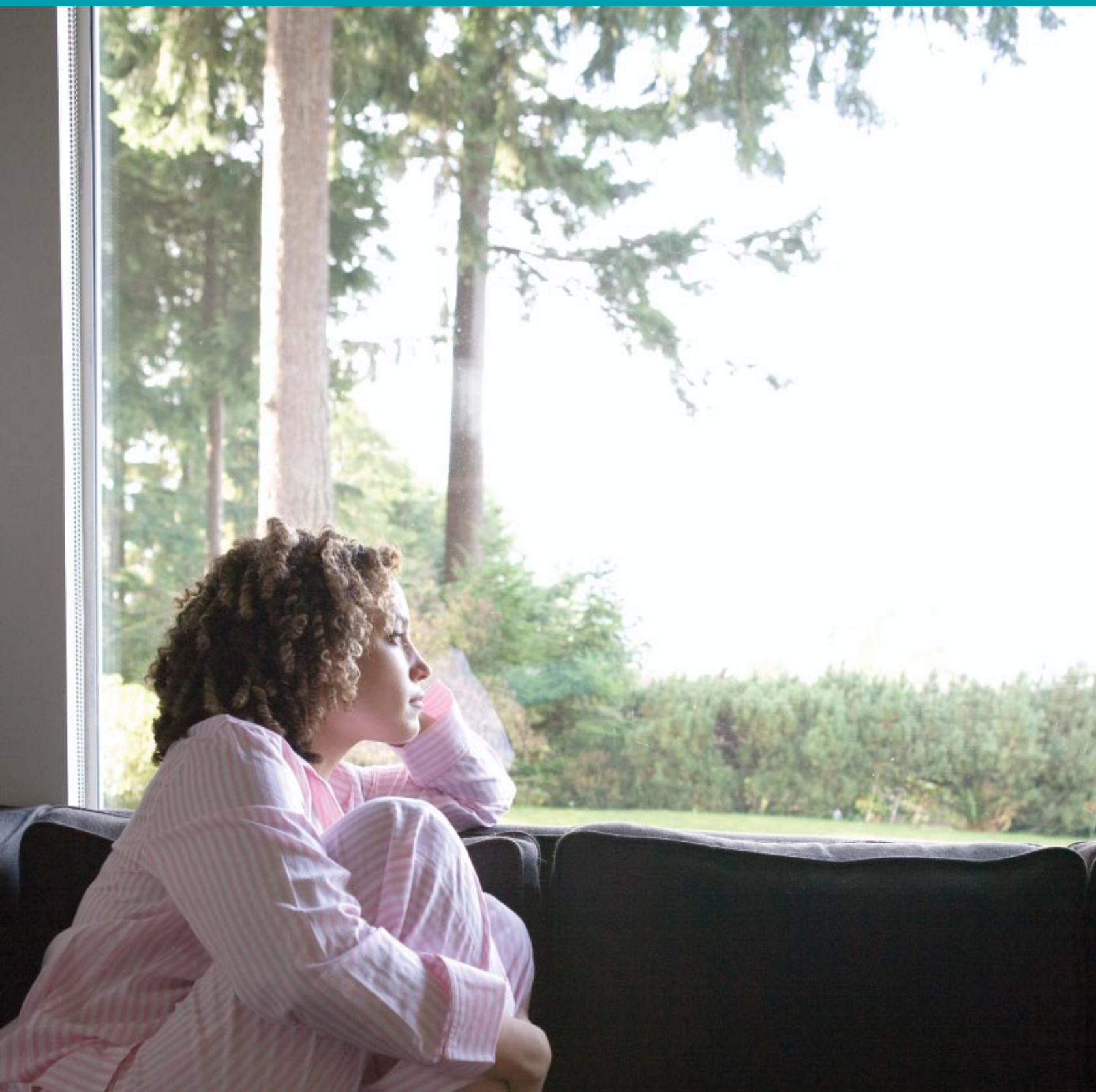
In addition to this booklet, we encourage you to reach out to your local NOCC Chapter to find support groups in your area. You can also call 1-888-OVARIAN or visit www.ovarian.org for more information.

With support and encouragement,

National Ovarian Cancer Coalition



When Ovarian Cancer Returns



Understanding Recurrence

Although most ovarian cancers respond well to initial chemotherapies, a majority of women diagnosed with advanced stage disease will experience a recurrence of cancer.

If ovarian cancer recurs, your doctor and healthcare team will focus on controlling the spread of cancer by using the most effective chemotherapy treatments available. At the same time, it is important to ensure that you maintain the highest possible quality of life by minimizing and controlling any treatment-related side effects.

By staying informed and actively communicating with your healthcare team, you can help ensure that you get the best possible treatment for your recurrence.

Time to Recurrence

An important concept to understand in ovarian cancer is 'time to recurrence.' This refers to the time between your initial complete response to platinum-based chemotherapy and a diagnosis of recurrent ovarian cancer. Based on time to recurrence, ovarian cancer is generally classified as either platinum-sensitive or platinum-resistant. This classification influences a woman's prognosis as well as the type of chemotherapy selected for treatment of recurrent ovarian cancer.

Platinum-Sensitive Cancer

Generally, if ovarian cancer recurs 6 months or more after primary platinum-based chemotherapy, it is classified as platinum-sensitive disease. This means that the cancer is responsive to platinum-based chemotherapy and is likely to respond to re-treatment with the same platinum-containing therapies used after initial diagnosis.

Women with platinum sensitivity have the greatest number of potential options for second-line therapy. Recent evidence suggests that combination chemotherapy may be superior to single-agent therapy in this situation.



Platinum-Resistant Cancer

If ovarian cancer does not respond to primary treatment with a platinum agent (such as cisplatin or carboplatin), or if the cancer returns within less than 6 months of completing primary chemotherapy, the cancer is considered 'platinum resistant.'

Women who have been diagnosed as having platinum-resistant ovarian cancer are unlikely to benefit from re-treatment with the same chemotherapy drugs that were used before. In these cases, other types of chemotherapies will be used to control the cancer. More information on the treatment of platinum-resistant ovarian cancer can be found on page 8.

Supportive care and an emphasis on optimal symptom management also can help ensure that every woman can maintain the best possible quality of life during this time. In addition, it is important to consider the possibility of participating in clinical trials that evaluate the benefit of investigational treatments.

Platinum Sensitive

- Cancer recurs after 6 months or more of remission
- Responsive to platinum-based therapy
- Often treated with more than one agent

Platinum Resistant

- Recurs less than 6 months after initial treatment
- Not responsive to platinum-based therapy
- Usually treated with non-platinum single agent

By staying informed and actively communicating with your healthcare team, you can help ensure that you receive the best possible treatment for your recurrence.

Key Considerations for Selecting Treatments for Recurrent Ovarian Cancer

Time to Recurrence/ Time to Re-Treatment

- How long has it been since my last chemotherapy?
- How soon should treatment be restarted?

Toxicity

- What was the worst toxicity or side effect of my last chemotherapy?
- What side effects would I like to avoid (if possible) with additional chemotherapy?

Delivery Schedule/Ease of Administration

- Is a weekly schedule or monthly schedule better for me?
- Is intravenous (IV) access a problem for me?
- Is intra-peritoneal (IP) delivery an option for me?

Quality of Life

- What are the most important quality of life issues for me?

Investigational Therapies

- Am I a candidate/do I want to consider participating in a clinical trial?



Open your heart and your mind so the good things in life can come in.

Taking Charge with Recurrent Disease

It is difficult to learn you have recurrent cancer, but the sooner you accept the diagnosis, you can begin to educate yourself and work closely with your doctor to make important treatment decisions. The more you are involved, the more you can take back control of your life.

Empower Yourself with Knowledge

You've already taken the first step by learning as much as you can about managing recurrent cancer and taking care of yourself during this challenging time. Remember, there is a lot of information out there. Try to focus on gathering information from credible sources such as your healthcare team, leading cancer advocacy organizations, cancer centers and government web sites.

Dealing with Your Emotions

Learning that your cancer has returned will stir up many emotions. You may feel angry, vulnerable, scared or sad. It is important to be aware of your emotions and not keep them bottled up. Try to share your feelings with a family member or close friend. Some women find it helpful to spend time with a religious or spiritual advisor to discuss their feelings.

Sometimes, as women focus on treating the cancer, they ignore their emotional well-being. Caring for your emotional well-being will ensure that you are able to focus and work with your doctor to devise the best treatment plan possible.

Managing Depression

Many women with ovarian cancer experience some form of anxiety and/or depression following a recurrence. Common signs of depression include loss of appetite, difficulty sleeping or sleeping too much, general lack of interest in activities, inability to communicate, loss of concentration, prolonged feelings of sadness and grief, wide mood swings, loss of sex drive and suicidal thoughts.

Let your healthcare team know if you experience any of these symptoms for longer than a two-week period. Medication and/or counseling can be very effective in treating depression. Without treatment, depression can interfere with your ability to make decisions about treatment. Equally as important, untreated depression can interfere with your ability to enjoy your family, friends and the activities that bring you happiness. For more on depression and anxiety, turn to page 26-27.

Enlisting Support

Family, friends and co-workers will want to help during this difficult time. Learn how to accept the support and encouragement of your loved ones.

Though accepting emotional and practical support can be difficult for many of us, it is important to do. Allowing loved ones to offer care and support can be incredibly rewarding and healing for all involved.

Remember, good communication is essential.

- Write down a list of specific things you need help with so people are clear about how they can help.
- Don't be shy about telling people how you are feeling. If you need some alone time – let them know. If you need a hug, ask for one.
- Try your best to communicate clearly and directly with loved ones and your healthcare team.
- Bring a family member or friend to your medical appointments. He or she can be a second pair of ears and can take notes.
- Bring a list of questions with you to every appointment. If you don't write them down, you might forget them!

“I felt really sad and couldn't concentrate or deal with everyday life. A friend suggested that I speak to someone. Talking to a professional helped me deal with the situation and the large scope of emotions I was feeling.”

Understanding Treatment Options



Once you have been diagnosed with recurrent cancer, there are many important treatment-related issues to consider: When should treatment begin? What medications should be used and in what order? How will these medications affect my quality of life?

When Should I Begin Treatment (Now or Later)?

Depending on whether the recurrent cancer is platinum-sensitive or platinum-resistant, you and your doctor will discuss when (or if) to begin treatment and what type of treatment might be best for you.

If a woman has evidence of disease based on a physical exam or radiographic evidence (e.g. CT scan), or is experiencing symptoms of disease, most doctors will immediately initiate treatment.

Treatment Based on Rising CA-125

There are differing viewpoints in the medical community about starting treatment for possible recurrence based on rising CA-125 levels alone. While rises in CA-125 can cause alarm and concern among many women, they do not always signify a relapse. Other conditions can cause transient increases in CA-125 levels.

If you do not have physical or radiographic evidence of disease recurrence, speak with your doctor about whether you should start treatment based on rising CA-125 levels.

Every situation is unique, so there is no single, correct answer. Ask your doctor about his/her position on this topic, in general, and about your case, in particular.

Developing an Individualized Treatment Plan

Once you and your doctor have agreed to begin treating the recurrence, your doctor will work closely with you to develop your individualized treatment plan.

There are many treatments available for recurrent ovarian cancer. The following is a list of questions that you and your doctor will discuss as you make important treatment decisions.

The answers to these questions affect the choice of treatment(s) and may affect your eligibility to enter a clinical trial:

- How long after your initial treatment did your disease recur?
- How many prior regimens have you had and which specific drugs have you taken?
- What side effects did you experience with your previous treatment (e.g. low blood counts, nausea and vomiting, peripheral neuropathy)?
- What symptoms are you currently experiencing?
- Do you have any stomach or bowel problems?
- What is your current level of functioning?
- What is the location and size of your current tumor?
- If the cancer is platinum resistant, are there other drugs that it is also likely to be resistant to?
- Are you able to eat/tolerate food?
- What are your goals with regard to further treatment?

As you consider treatment for recurrent ovarian cancer, it is very important that you discuss your and your doctor's goals for treatment. For most women, the most important goal is to keep the cancer under control in order to extend their lives. However, it is also important to talk about other important goals such as controlling disease-related symptoms, avoiding side effects of treatment and maintaining the highest possible quality of life.

Optimizing Quality of Life

When making treatment decisions, it is important to weigh the possible benefits of treatment (remission, longer survival) with risks of treatment side effects that reduce quality of life. Be sure to discuss issues related to quality of life with your doctor.



Intraperitoneal (IP) Delivery

The National Cancer Institute recommends that women with advanced ovarian cancer who undergo effective surgical debulking receive a combination of IV (intravenous) and IP (intraperitoneal) chemotherapy. Intraperitoneal therapy is delivered through a port located in the stomach.

IP chemotherapy allows higher doses and more frequent administration of drugs and appears to be more effective in killing cancer cells in the peritoneal cavity, where ovarian cancer is likely to spread and recur first. Studies suggest that IP therapy results in improved overall and progression-free survivals.

Certain chemotherapy drugs, such as cisplatin and paclitaxel have been found to have distinct advantages when given via the IP route. These advantages include higher drug concentrations and longer drug half lives (meaning the drug will remain active for a longer period of time) in the peritoneal cavity.

It is important to note that IP therapy has only been studied in frontline therapy. Use of IP chemotherapy in the recurrent setting is unproven to be efficacious or safe. Many do not recommend its use in recurrent disease outside of a clinical trial period.

Should Surgery Be Considered?

While surgery is an important part of the initial diagnosis and treatment of ovarian cancer, it is unclear whether surgery benefits women after a recurrence. In most cases of recurrent disease, the cancer is not in a single mass that can easily be removed by the surgeon. However, if it has been a long time since your initial treatment, surgery may be considered, depending on where the disease is and how much disease is present. If your disease returned soon after initial treatment, surgery generally is not recommended.

Surgery for recurrent ovarian cancer is generally not recommended unless there is clear evidence that the cancer can be removed surgically.

Treatment for Platinum-Sensitive Ovarian Cancer

If you experience a recurrence more than 6 months after initial therapy, you are considered platinum sensitive, and you have a number of potential options for second-line therapy. In this case, recent evidence suggests that combination therapy (combining more than one chemotherapy drug) may be superior to single-drug therapy for women with platinum-sensitive recurrent cancer.

Your doctor will discuss specific treatment options with you. A list of medications used to treat recurrent ovarian cancer and their side effects appears on the following pages.

Treatment for Women with Platinum-Resistant Cancer

If you have platinum-resistant cancer (see definition on page 3), it is unlikely that you will benefit from re-treatment with a platinum-based regimen. However, there are several secondary chemotherapy drugs that can be used to treat the recurrence.

Most doctors do not recommend combining more than one drug for treatment of platinum-resistant ovarian cancer, because there is no evidence that combination therapy is better than using a single drug. There is, however, evidence that combination therapy is more toxic to a woman's body.

Response rates remain disappointingly low for many secondary drugs. But in addition to women whose cancers respond to treatment, some women will attain "stable disease" on treatment. This means that although the cancer does not shrink significantly in size, it does not grow. When cancer is stable on a treatment and the treatment is well tolerated, most doctors will recommend continuing that treatment until the cancer begins to grow again.

When Supportive Care Makes Sense

If it is unlikely that additional chemotherapy will help, or if side effects have become too difficult, some women with platinum-resistant cancer decide to forgo chemotherapy and choose supportive care instead.

Supportive or palliative care means that an emphasis is placed on treating symptoms caused by the cancer or cancer treatment rather than on treatment of the cancer itself. The overarching goal is to relieve physical and emotional suffering and to improve the quality of a woman's life.

Common symptoms that are treated by palliative care include:

- Pain
- Difficulty breathing
- Loss of appetite and weight loss
- Fatigue
- Weakness
- Sleep problems
- Depression and anxiety

When starting a new treatment for recurrent ovarian cancer, it takes 2 to 4 cycles to determine if it is working. After 2 to 4 cycles your doctor should evaluate if your cancer is responding to the treatment.

Medications Used to Treat Recurrent Ovarian Cancer

The following is an alphabetical list of some commonly-used chemotherapy and hormonal drugs to treat recurrent ovarian cancer as noted in the 2006 National Comprehensive Cancer Network (NCCN) Practice Guidelines in Oncology. **Not all of these treatments are approved by the FDA for recurrent ovarian cancer.**

This list includes common side effects and toxicities. It is important to note, however, that each individual can be affected differently by each therapy. You may not experience the side effects listed, or you may experience side effects that are not listed here.

Also, keep in mind that the list may change as practice guidelines are updated. Talk with your doctor and check the NCCN web site www.nccn.org for the most current information.

Please discuss treatments and side effects with your doctor or nurse. Also note that some side effects may limit your ability to stay on specific treatments for extended periods of time. Your doctor may consider switching you to another medication with fewer or different side effects.

Altretamine (Hexalen®)

Route and Schedule

Pills given orally 3 times a day for 14 days every 21 or 28 days

Side Effects

Nausea/vomiting (can limit ability to take drug)
Reduction in white blood cell count (less common)

Capecitabine (Xeloda®)

Route and Schedule

Pills given orally twice a day with food for 14 days every 21 days

Side Effects

Skin changes (red, peeling skin of hands/feet)
Mouth sores (sometimes)
Nausea/vomiting if not taken with food
Infrequent reduction of white blood cells

Carboplatin (Paraplatin®)

Route and Schedule

IV given over 15 minutes to an hour every 3 to 4 weeks

Side Effects

Moderate reductions in white and red blood cells and platelet counts
Moderate nausea and vomiting
Loss of appetite
Numbness and tingling in extremities
Slight risk of allergic reaction
Hair loss: none to mild

Possible dose-limiting toxicity:

Decrease in platelet counts

Cisplatin (Platinol®)

Route and Schedule

IV given slowly over 1-2 hours every 3 to 4 weeks

Side Effects

Severe nausea and vomiting that can last up to 5 days
Kidney damage
Low magnesium
Nerve damage in hands and feet
Hearing loss

Decreases in white and red blood cells, and slightly in platelets; can cause anemia
Hair loss: none to mild

Possible dose-limiting toxicities:

Kidney damage, nerve damage, hearing loss

Cyclophosphamide (Cytosan®)

Route and Schedule:

IV given over 30 minutes by IV or oral tablets as directed

Side Effects

Moderate to severe decreases in white and red blood cells and platelet counts
Bloody urine and bladder inflammation
Nausea and vomiting
Complete hair loss

Possible dose-limiting toxicities:

Bone marrow suppression and possible cardiac issues

Docetaxel (Taxotere®)

Route and Schedule

IV given over 1 hour every 3 weeks

Side Effects

Severe decreases in white and red blood cells and platelet counts

Nausea, vomiting and diarrhea
Fluid retention

Risk for allergic reaction/rash

Complete hair loss

Possible dose-limiting toxicity:

Nerve damage in hands and feet

Oxaliplatin (Eloxatin®)

[given with 5-fluorouracil/leucovorin]

Route and Schedule

IV infusion for 48 hours (Eloxatin only given during first 2 hours) every 14 days as directed by doctor

Side Effects

Reduction in white and red blood cells and platelets

Nausea and vomiting

Diarrhea

Mouth sores

Tingling and numbness in hands and feet

Liposomal doxorubicin (Doxil®)

Route and Schedule

IV over 1-3 hours once every 3 to 4 weeks

Side Effects

Skin changes (red, peeling skin of hands and feet)

Mouth sores

Reduction of white blood cells (common), red blood cells and platelets

Nausea and vomiting

Loss of appetite

Hair loss (mild)

Possible dose-limiting toxicity:

Hand and foot syndrome

Gemcitabine (Gemzar®)**Route and Schedule**

IV over 15-30 minutes weekly for 3 out of 4 weeks

Side Effects

Decrease in white and red blood cells/platelets

Nausea and vomiting

Diarrhea

Rash and itching

Flu-like symptoms

Mouth sores

Fluid retention

Mild to moderate hair loss

Irinotecan (Camptosar®)

[given with 5-fluorouracil/leucovorin]

Route and Schedule

Infusion which takes 24-48 hours (6 times over 42-day treatment cycle) or by Bolus Injection which takes 5-10 minutes (5 times over 42-day treatment cycle)

Side Effects

Early and late diarrhea

Reduction in white blood cells

Melphalan (Alkeran®)**Route and Schedule**

Tablets daily for 5 days, every 4 to 5 weeks

Side Effects

Bone marrow suppression

Mouth sores

Infrequent nausea, vomiting and diarrhea

Possible dose-limiting toxicity:

Bone marrow failure

Oral Etoposide (VePesid®)**Route and Schedule**

Capsule given orally once a day for 2-3 weeks with 2 weeks off

Side Effects

Decrease in red and white blood cells and platelets

Nausea and vomiting

Loss of appetite

Hair loss (complete)

Possible dose-limiting toxicity:

Risk of secondary leukemia

Paclitaxel (Taxol®)**Route and Schedule**

IV given over 30 minutes daily 5 days per week, every 3 weeks or available in weekly doses

Side Effects

Reductions in white and red blood cells and platelets

Numbness in hands and feet

Nausea and vomiting

Diarrhea and/or constipation

Loss of appetite

Complete hair loss

Possible dose-limiting toxicity:

Nerve damage in hands and feet

Topotecan (Hycamtin®)**Route and Schedule**

IV daily for 30 minutes daily for 5 days a week every 3 weeks

Alternative schedule: weekly

Side Effects

Moderate to severe reduction in white and red blood cells and platelets

Nausea and vomiting

Fever, headache, fatigue

Mild to moderate hair loss

Vinorelbine (Navelbine®)**Route and Schedule**

IV over 15-30 minutes weekly for 3 out of 4 weeks

Side Effects

Reduction of white blood cells

Numbness and tingling in hands and feet

Nausea and vomiting

Hair loss (uncommon)

Anastrozole (Arimidex®) [hormone]**Route and Schedule**

Tablet taken daily

Side Effects

Hot flashes

Joint symptoms

Weakness

Mood changes

Pain

Sore throat/headache

Nausea and vomiting

Depression

High blood pressure

Osteoporosis

Swelling of arms/legs

Letrozole (Femara®) [hormone]**Route and Schedule**

Tablet taken daily

Side Effects

Hot flashes

Night sweats

Nausea

Tiredness

Weight gain

Vaginal bleeding

Joint pain

Tamoxifen citrate (Nolvadex®) [hormone]**Route and Schedule**

Oral tablets or liquid taken daily

Side Effects

Hot flashes

Changes in vision

Infrequent rash

Infrequent fluid retention

Risk for blood clotting

Note: Check with your pharmacist or insurance company to see if the drugs are covered under your insurance plan.

If your insurance company does not cover one of your treatments, or you cannot afford a treatment, call the pharmaceutical company who makes the product and speak with them about their patient assistance program. Many companies have a dedicated hotline for these requests and are able to provide reduced or no-cost drugs to people in need.

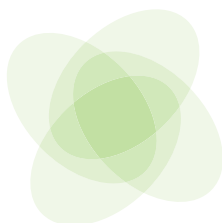
To obtain a copy of the National Comprehensive Cancer Network's Patient Guidelines for the treatment of Ovarian Cancer, call 888.909.NCCN or visit www.nccn.org.

Extreme Drug Resistance Assay

A test called the “Extreme Drug Resistance Assay” (EDR Assay) involves taking cells from your cancer, growing them on a plastic plate in the laboratory, and testing the effects of many different chemotherapy drugs on them.

The purpose of this test is to show which drugs are not likely to work for your cancer. However, this test has never been confirmed clinically, meaning that what has been shown in the lab has not been shown in patients.

Due to lack of evidence, the National Comprehensive Cancer Network does not currently recommend this approach as a way to determine which chemotherapy drugs to use.



Understanding Clinical Trials

In clinical trials, patients volunteer to participate in research studies designed to evaluate the effectiveness of new treatments. Many advances in the treatment of ovarian cancer today are a result of the information gained from previous clinical trials.

Clinical trials are conducted in most hospitals and cancer treatment centers across the U.S. To ensure the reliability of the data and the safety of all participating patients, all clinical trials evaluating medications are conducted under the strict guidelines of the U.S. Food and Drug Administration (the FDA).

Today, clinical trials in ovarian cancer are investigating new chemotherapy drugs, new combinations of drugs and exciting new therapies such as biologic agents.

Deciding if a Clinical Trial is Right for You

Deciding whether or not to join a clinical trial requires a lot of thought and consideration. It is a decision you should make with your doctor and your family.

Some things to keep in mind include:

Clinical trials are open only to people who meet the very specific health and cancer-related criteria for that study. This is done to ensure that the study can answer very specific scientific questions. Therefore, you may find that you are not eligible to participate in all ovarian cancer trials.

- A potential benefit of enrolling in a clinical trial is that participants can be among the first to receive experimental treatments before they are available on the market. It is important to remember, however, that it is not known whether these treatments are effective and they may have significant side effects.
- If you decide to enter a clinical trial, it is your right to withdraw at any time if you no longer want to be a part of the study.

Clinical trials can offer hope – especially to women with recurrent cancer. By participating, you contribute to the science of improving treatment for women with recurrent ovarian cancer.



Questions to Ask When Considering a Clinical Trial

- What is the purpose of the study?
- Who is conducting the trial?
- Am I eligible to participate?
- What type of treatment or tests will I have to take?
- Does the treatment have side effects?
- Why do the researchers believe the treatment may be effective?
- Has the treatment been tested before?
- How long will the study last?
- Will my insurance cover the costs?
- Will my doctor be able to stay involved in my care?

Find Out More about Clinical Trials

The following resources will help you learn more about clinical trials, and find ovarian cancer trials that might be appropriate for you. In addition to these resources, you should discuss clinical trials with your doctor. He or she may have helpful information to offer regarding new clinical trials.

National Ovarian Cancer Coalition

1-888-OVARIAN

www.ovarian.org

The leading ovarian cancer public information and education organization in the United States. Help and hope for women with ovarian cancer and their families provided through a network of volunteer-led chapters, toll-free helpline, comprehensive website, peer support, informational literature and special awareness projects.

Cancer Trials Support Unit

1-888-823-5923

www.ctsu.org

The Cancer Trials Support Unit is a pilot program of the National Cancer Institute (NCI) to make NCI-supported cancer treatment trials available to physicians nationwide.

Coalition of National Cancer Cooperative Groups

1-877-520-4457

www.cancertrials-help.org

This organization is comprised of cancer clinical trials specialists and offers a variety of programs and information for physicians, patients and advocates that are designed to increase awareness of, and participation in, cancer clinical trials.

National Cancer Institute

1-800-4-CANCER

www.cancer.gov

The National Cancer Institute is the cancer-specific arm of the U.S. National Institutes of Health. Its website provides comprehensive information about all matters related to cancer including clinical trials.

National Comprehensive Cancer Network

1-888-909-6226

www.nccn.org/clinical_trials

The National Comprehensive Cancer Network (NCCN), a not-for-profit alliance of 20 of the world's leading cancer centers, is dedicated to improving the quality and effectiveness of care provided to patients with cancer.

Preparing for Treatment

When you plan ahead, you can be prepared for anything, and can meet the challenges of cancer head-on.

Treatment for ovarian cancer can take a lot out of you physically and mentally. During your treatment, it is likely that you will have to alter your schedule and approach your life a bit differently. The cancer treatment may cause symptoms and side effects that will affect your ability to take care of yourself or go to work – not to mention caring for your husband/partner or kids.

It is important to be realistic about how your treatment might affect your day-to-day life and to make plans to prepare for these changes in advance. Enlisting the support of your loved ones can greatly help you get through treatment.

Helpful Tips

Make a calendar of your treatment schedule and share this with family, friends and co-workers.

Ask for time off from work. If you can, consider going on disability. At a minimum, see if your duties at work can be temporarily lightened to accommodate your treatment and your reduced energy.

Make lists of key chores and responsibilities (e.g. taking the kids to school, walking the dog, grocery shopping, doing laundry, cooking).

Assign tasks to members of your family and friends to make sure all bases are covered.

Prepare mentally and emotionally to slow down the pace of your life during treatment; accept that this is not a weakness – but a smart way to take care of your mental and physical well-being.

Have a family meeting to discuss your treatment schedule and give everyone a chance to ask questions they might have.

Talk with your husband/partner, family and friends about how you are feeling (scared, anxious, etc.). These are normal feelings and are worth discussing.

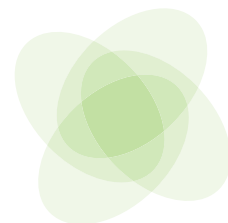
Simplify your life. For example, if you can: send your laundry out; have dinner delivered instead of cooking; have someone drive you to your chemotherapy appointment or take a taxi.

Sequence of Chemotherapy Planning Chart

When you are ready to begin treatment for recurrent ovarian cancer, you and your oncologist should work together to select the treatment(s) that will be most effective and appropriate for you. These decisions will be based on when you were diagnosed with recurrence, previous treatments you have taken, their side effects and toxicities, your current state of health as well as your wishes in terms of quality of life.

The chart on the following page can be used to track your treatment options as you and your doctor work together to select a sequence of therapies that takes future episodes of recurrence into account.

Bring this chart with you to your next appointment so you can plan your individualized current and future treatment plan with your doctor.



Chemotherapy Planning Chart

name of treatment	initial therapy	recurrence 1	recurrence 2	recurrence 3	recurrence 4
hormone					
other:					
other (clinical trial)					

Managing Your Treatment





Managing Side Effects

Most chemotherapy drugs cause side effects. Each chemotherapy drug has its own side effect profile and side effects also vary from person to person.

It may be possible for you and your doctor to structure your treatment plan to avoid or minimize certain side effects. Regular communication with your treatment team is key to managing side effects. Discuss the potential side effects of each treatment you and your doctor are considering. Keep in mind that chemotherapy affects everyone differently.

Once you start treatment, work closely with your doctor or nurse to ensure that your side effects are managed and you are able to maintain a good quality of life.

Some questions to discuss with your doctor and nurses include:

- What side effects might the treatment cause?
- How severe will the side effect(s) be?
- Do the potential benefits of the treatment outweigh the potential side effects?



Will these side effects interfere with my quality of life?

Pay close attention to how you feel and report any side effects you have to your doctor or nurse. The sooner they are aware of the problem, the sooner they can help you manage the problem.

Following are some of the most common chemotherapy side effects and helpful tips to manage them.

Fatigue and Anemia

If you feel physically, emotionally or mentally exhausted and have difficulty concentrating or thinking clearly, you may be suffering from fatigue.

The most important thing to understand about cancer-related fatigue is that it is REAL. It is not in your head. It is the most common side effect of cancer and cancer treatment and it can have a huge impact on your quality of life. Fatigue needs to be taken seriously by you, your family and friends, and your healthcare providers.

The exact cause of cancer-related fatigue is not known, but there are many things that can contribute to it. Some of the most common causes are the cancer itself, chemotherapy or radiation used to treat the cancer, low red blood cell counts (anemia), nutritional problems, sleep problems, depression and emotional concerns such as fear, worry or anxiety.

If your fatigue is caused by anemia, you have fewer red blood cells to transport oxygen throughout your body. This can lead to feelings of extreme tiredness, headache, shortness of breath and difficulty sleeping. If you feel so tired that you can't do your normal daily activities such as taking a shower, making the bed, cooking or climbing stairs, talk to your healthcare team about anemia. They can do a simple blood test to determine if you have anemia. If so, it can be treated with medications called erythropoietic agents.

What you can do to manage cancer-related fatigue:

While you may not be able to prevent or avoid fatigue altogether, there are things you can do to help reduce your fatigue. These recommendations can be organized into 5 types of activities:

1) Energy Conservation

Plan, prioritize and pace activities throughout the day. Adapt your activities based on your energy levels. When possible, practice efficiency in your activities (e.g. using the dishwasher instead of washing dishes by hand). Take breaks whenever you feel tired.

2) Energy Restoration

Take time out for things you really enjoy and that make you feel good. Some activities can actually make you feel more energized. Listening to music, reading, meditation, spending time with friends and loved ones and taking a walk in the park are some examples of activities that people have said make them feel less tired.

3) Rest

Rest and sleep are important, but too much sleep can actually make you feel more tired. The most important thing is to get good, restful sleep at night. If you feel like you need to nap, take short naps or breaks rather than one long nap during the day. Short naps (less than 30 minutes) can energize you, whereas long ones may leave you feeling more fatigued and may interfere with your overnight sleep.

4) Activity

It is important to continue to do some exercise. Inactivity leads to muscle loss which increases fatigue. Walking is a great way to get exercise. Research has shown that 20-30 minutes of exercise (such as walking) 3-5 times a week can reduce feelings of cancer-related fatigue. Talk to your doctor prior to starting an exercise program to make sure there are no limitations to the kind of exercise you do.

5) Nutrition

Good nutrition is even more important than usual when you have cancer-related fatigue. At the same time, you may have trouble eating due to fatigue, poor appetite, nausea, vomiting or feelings of fullness. It may be helpful to eat small, frequent meals. If you are too tired to prepare food, allow someone else to cook for you or use frozen or easy to prepare foods. Talk with your nurse or doctor if you are having difficulty eating or if you are concerned about the quality of your diet. They can give you nutrition tips or arrange for you to meet with a nutritionist.



Pain

Cancer pain can occur as a result of tests, surgery, chemotherapy, radiation therapy, hormonal therapy or from the tumor pressing on other tissues. With proper treatment, most patients can get relief from cancer pain.

The most important thing is to let your doctor or nurse know if you have pain. They cannot know if you are in pain unless you tell them. Women often don't report pain because they don't want to bother the doctor or nurse. Women also say they do not want to appear to be complaining. But your healthcare team wants and needs to know if you're having pain. Good pain management helps you better participate in your treatment and will improve your quality of life.

Many pain medicines are available to relieve your pain. These may include nonsteroidal anti-inflammatory drugs (e.g., aspirin, ibuprofen), opioids (e.g., codeine, morphine), antidepressants, anticonvulsants, corticosteroids and others.

Helpful tips for controlling your pain include:

- Be sure to take your pain medicine as prescribed. The best way to take medicine is on a schedule (e.g., every 4 hours). Waiting until the pain returns may mean you will need to take more medicine than if you treat the pain before it becomes a problem.
- Take supplemental, or as-needed pain medicines before any activity you know will be painful. This will allow you to be active with less pain.
- Let your doctor or nurse know if you are having side effects from the pain medicines. Most side effects can easily be treated.
- Most people taking opioid medicines will develop constipation. Take a laxative and stool softener (either as separate pills or in combination) every day to prevent constipation. As the dose of the opioid increases, so must the dose of the laxative and stool softener.
- Complementary therapies such as relaxation, guided-imagery exercises, acupuncture, distraction and massage therapy can be very helpful in addition to your pain medicines.

If your pain is not well-relieved with the medicines ordered, let your doctor or nurse know as soon as possible. Many medicines are available and everyone responds differently to each medicine. You may need to try several medicines before finding the one most effective for you.

Hair Loss

Hair loss is one of the most dreaded side effects of chemotherapy. This side effect is particularly difficult because it is so public and because it directly relates to our self image. Some chemotherapy drugs do not cause hair loss, some cause only thinning, while others cause complete hair loss.

The following are suggestions from other women who have gone through the experience of hair loss:

- Many women find it helpful to have their hair cut into a shorter style before they lose their hair.
- Wearing a scarf or hair net to bed will help to prevent hair from collecting all over your pillow.
- Some women prefer to shave their head when hair loss begins. This sometimes helps to minimize scalp discomfort.
- It is helpful to shop for a wig before you experience hair loss in order to be able to match your style, color, and texture as closely as possible. Others opt not to wear a wig and instead use hats or scarves.
- Still others choose not to wear any head covering at all. If you choose not to wear a head covering, it is important to use sunscreen while you are outdoors.
- If your treatment doesn't cause hair loss, it may still become fragile and dry. Treat your hair gently – use mild shampoos, a soft hairbrush and avoid dyes, rollers, hair sprays and permanents.

Nausea and Vomiting

Nausea and vomiting are best managed by using several approaches simultaneously, tailored to the type of nausea you are experiencing. Approaches include medications, practical food and fluid intake, and complementary or additive therapies such as relaxation, guided imagery, acupuncture, acupressure, hypnosis or distraction.

Anticipatory nausea and vomiting occurs before treatment is given. It is best treated with anti-anxiety medications given the night before and the morning of treatment. The medication helps to ease tension and break the cycle of this type of nausea and vomiting. Studies have found that this type of nausea and vomiting also responds well to complementary therapies.

Acute nausea and vomiting which occurs within 24 hours of chemotherapy treatment is generally managed with anti-emetic medication. If the chemotherapy regimen is highly associated with nausea and vomiting, a prescription is given for an oral medication to be taken at home. It is important to take this medication on a regularly scheduled basis for the first 2-3 days after treatment. It should be taken regularly, even if you do not feel nauseated when it is time to take a pill. This regular dosing is done to prevent nausea from occurring.

- **Relax Before Treatments** – Sometimes nerves or the thought of the treatment can trigger an upset stomach.
- **Avoid Greasy High-Fat Foods** – Stay away from fried foods, potato chips, hamburgers, etc.
- **Eat and Drink Slowly** – Chew food well and take small sips of fluids.
- **Rest After Eating** – Stay upright. Do not lie flat for at least one hour after eating.
- **Stay Hydrated** – After vomiting, sip clear, cool beverages or suck on ice cubes or popsicles.
- **Take Anti-Nausea Medication as Prescribed** – If it is not working, talk to your doctor about changing your medication or the medication schedule.

Constipation and Diarrhea

During your treatment, you may experience difficulty passing stool (constipation) or you may have loose stools (diarrhea). These changes in your bowel habits can be caused by your cancer treatment, changes in your diet, pain medication (constipation) and/or inactivity.

If you experience severe stomach pain, cramping or diarrhea for more than a day, call your doctor right away.

Avoiding/Controlling Diarrhea

Drink Plenty of Fluids – Mix grape, apple or cranberry juice with water for better tolerability.

Do Not Eat High Residue/High Fat Foods – This includes whole wheat and whole grain breads, popcorn, seeds and nuts, raw vegetables, dried fruit and fruit with skin and high-fat foods.

Add Soluble Food to Your Diet – This includes oatmeal, potatoes, apricots, bananas, white rice, peeled apples, pears and peaches.

Eat Small Meals, Often

Use Reduced-Lactose Products

Avoid Caffeine

Call Your Doctor – Check with your doctor before you take antidiarrheal medications or if you have a fever, bloody stools or severe cramps.

Avoiding/Alleviating Constipation

Drink Plenty of Fluids (8-10 glasses/day) – Non-caffeinated and warm fluids can be helpful.

Eat High-Fiber Foods – Plant-based foods such as vegetables, fruits and beans and certain grains add fiber to your diet.

Move Around as Much as Possible – Take a walk to stimulate bowel movements.

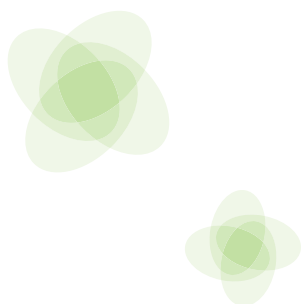
Try to Move Your Bowels at the Same Time Every Day

Add a Fiber Laxative to Your Diet

Talk to Your Doctor Before Using Suppositories

(laxatives other than fiber, stool softeners or enemas)

– Taking the wrong treatment can make your condition worse. Some of these treatments should not be used when your white blood counts are low.



Mouth and Throat Problems (Mucositis)

Chemotherapy drugs can affect the lining of your mouth, throat and tongue and can cause you to have difficulty swallowing. In addition, the tissue in your mouth can be irritated and dry, which can cause appetite loss, mouth sores and infection.

The best way to prevent or minimize mouth sores is through good oral hygiene. Use a soft toothbrush and keep your mouth moist. On the day before chemotherapy and for 3-5 days following treatment, rinse your mouth with cool water frequently and drink plenty of cool beverages or suck on ice chips or popsicles. Avoid food that can irritate the inside of your mouth such as: hot or spicy foods, salty foods, hard or coarse foods, alcoholic beverages, acidic foods (such as tomatoes or citrus fruits/juices), tobacco and mouthwashes or toothpastes that contain alcohol or hydrogen peroxide. If despite your best efforts you still develop mouth and throat problems, there are measures to help relieve your symptoms. They include:

- Sucking on ice chips, popsicles and watermelon.
- Choosing soft foods such as milk shakes, baby food, mashed potatoes, eggs, custards and puddings.
- Use a salt and soda mouthwash (1 teaspoon salt and 1 teaspoon baking soda in 1 quart of water) to rinse your mouth frequently.
- Talk to your healthcare provider about topical products such as viscous lidocaine or magic mouthwash to provide pain relief, or medications such as Sucralfate and Gelclair that coat the inside of your mouth.
- Talk to your doctor about systemic pain medication for relief if needed.

Fighting Infection

Many chemotherapy drugs can cause a reduction in the number of white blood cells in your body - making you more likely to develop an infection. During your treatment, even minor infections can become a problem, which is why it is important during this period of vulnerability to take special precautions to protect yourself.

- **Avoid Cuts and Scrapes** – Be careful when using knives, scissors, needles and shavers. If you accidentally cut yourself, clean the wound immediately.
- **Wash Hands Often** – You and your family should wash hands before eating and after using the toilet and touching things in public places.
- **Avoid Crowds** – Go shopping or do other activities at less-crowded times of day.
- **Trim Your Nails Carefully** – Avoid nail biting or tearing your cuticles.
- **Take a Warm Bath or Shower Daily** – Pat your skin dry and use moisturizer to avoid dry skin.
- **Avoid People with Colds, Coughs, Flu or Other Contagious Illnesses.**
- **Drink Plenty of Fluids** – This may help you avoid getting a urinary tract infection.

Nerve and Muscle Problems

Chemotherapy sometimes can affect the muscles and nerves causing you to experience tingling, burning or numbness in the hands and feet (peripheral neuropathy), or loss of balance and clumsiness. It can make it difficult to pick things up and to use your hands for things like buttoning a shirt. If you experience these symptoms, talk to your doctor. He or she may be able to suggest ways to manage the neuropathies or may need to alter your chemotherapy drug or dosage.

Prevention: It may not be possible to entirely prevent peripheral neuropathy from occurring. Several therapies such as vitamin B6 and glutamine have been used with varying degrees of success. It is important that you discuss the use of these medications with your healthcare provider. It is not advisable to take any medications, even over-the-counter products, (this includes vitamins and herbal supplements) that your healthcare provider is unaware that you are taking. There may be interactions with other drugs that you are taking or side effects from these medications.

Management: You should be aware of treatments that are available to help minimize your discomfort and strategies to help keep you safe. Medications such as non-steroidal anti-inflammatory agents (Advil, Naproxen) can be used to treat mild discomfort. Your healthcare provider may prescribe other classes of medication such as anti-depressants (Pamelor, Elavil) and anti-convulsants (Neurontin) to help specifically with nerve pain. Additionally, topical analgesics (Lidocaine patch, EMLA cream, Capsaicin, or Tiger Balm) may be helpful. Other therapies that have been tried include the use of TENS units and acupuncture.

Safety is an important issue when your sense of feeling is impaired. Important safety measures include:

- Wear sturdy, non-slip shoes and use care when walking.
- Remove throw rugs to prevent slipping.
- Make sure stairways are clear and well-lit.
- Be careful when bathing. Use non-skid bathmats and use warm (not hot) water. Consider using a shower chair and hand rails.
- Use pot holders to prevent burns when cooking.
- Wear gloves when doing household chores.
- Use hand rails to prevent falls on stairways.
- If you drive, make sure that you can feel the gas and brake pedals with your foot; if not, have someone else drive you where you need to go.

Skin Irritation

Chemotherapy drugs can cause rashes, itching, peeling skin and can cause your skin to be more sensitive to the sun. Cracked and irritated skin can be more prone to infection, so it is important to take care of your skin during your treatment.

Protect the Skin – Try to keep skin from becoming dry, chapped or sunburned. Use hypoallergenic moisturizer and sunscreen with SPF 15 or above and avoid excessive scratching. Do not use lotions, powder or deodorants with perfumes as they can increase the potential for irritation.

Let Skin Breathe – Wear loose-fitting clothes made from soft, natural fibers to avoid chaffing.

Stay Clean and Dry – Use mild soap when bathing, rinse and pat dry. Avoid using hot water when bathing to prevent skin irritation.

Nutrition

As you undergo cancer treatment, you may lose your appetite. Proper nutrition is always important, but is especially necessary when you are fighting cancer. Eating nourishing food that is high in protein is very important. During the course of your treatment, your doctor may refer you to a nutritionist. This specialist can help design a good nutrition plan that you can follow easily.

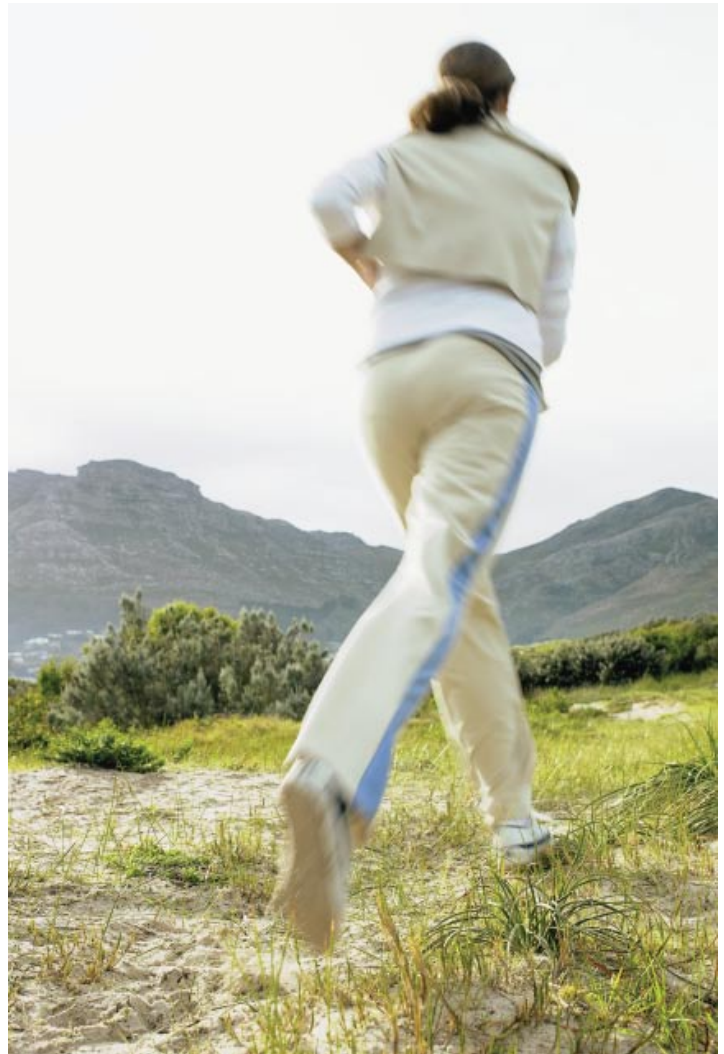
Maintain a Well-Balanced Diet – If you feel nauseated, eat plain carbohydrate foods such as white rice, crackers, toast, pretzels and pasta. Eat high-nutrient foods like cheese, lean meats, cereal, milk and eggs.

Eat Smaller, More Frequent Meals – Set a routine in which you eat smaller portions more often through the day.

Snack Between Meals – Have a high-protein diet supplement or milkshake to add calories and nutrients.

Plan Meals – Decide your menus in advance and freeze extra meals to simplify your cooking schedule.

Make Eating Enjoyable – Dine with family or friends, play music or set a mood with candles.



Exercise

While it might be the last thing on your mind when you have cancer, exercise (if approved by your doctor) can help you gain energy, build and maintain strength, boost the immune system and relax your mind. Even a small amount of exercise can be beneficial.

Clear all Exercise with Your Doctor Before Starting – Discuss what type/level of exercise is appropriate for you.

Consider Low-Impact Activities – Walking, stretching and yoga are gentle ways to get back into exercise, raise your heart rate and regain strength.

Do not begin any exercise routine until you have spoken with your doctor and received his/her consent.

Complementary Therapies

Some women with ovarian cancer often turn toward the whole-body approach of complementary therapy to enhance their fight against the disease, as well as to relieve stress and minimize side effects such as fatigue, pain and nausea.

Complementary therapies are diverse practices and products that are used in conjunction with traditional medicine.

Many women have tried and benefited from the following complementary therapies. You might want to speak with other women with cancer or your healthcare team to see which therapies they found most helpful or might work best for you and your lifestyle.

Acupuncture – An ancient Chinese method of healing in which small sterilized needles are inserted into the body’s energy centers to promote healing.

Aromatherapy – The use of essential oils from flowers, herbs and trees to promote health and well being.

Herbal Medicine – Remedies using plant parts to treat symptoms and illnesses. (Consult your healthcare professional prior to using herbal medicine).

Massage – Manipulating the body’s muscle and connective tissue through rubbing, kneading and patting to promote relaxation and well-being.

Meditation – Conscious relaxation and focused breathing to relax the mind and body.

Qi Gong (chee-GUNG) – A type of Chinese medicine that combines movement, meditation and breathing to enhance the flow of qi (an ancient term given to what is believed to be vital energy) in the body, improve blood circulation and enhance immune function.

Yoga, Tai Chi – Postures, movements and breathing exercises to strengthen and heal the body, mind and spirit.

Safe Use of Complementary Therapy

While scientific evidence exists for some complementary therapies, such as acupuncture, for most, their benefit has not yet been proven through well-designed scientific studies, such as clinical trials. Before beginning any complementary therapy, it is important to discuss the approach with your doctor.



Complementary vs. Alternative Medicine

People are often confused about the difference between complementary and alternative medicine. As discussed in this section, complementary medicine makes use of non-conventional therapies such as acupuncture, yoga and meditation in addition to conventional treatments. Alternative medicine, on the other hand, refers to a treatment method that is used in place of standard treatment. By definition, alternative treatments are not integrated into a conventional treatment plan.

Quality of Life and Other Considerations



Your Life With Cancer – Make It Good!

“While we have the gift of life, it seems to me the only tragedy is to allow part of us to die – whether it is our spirit, our creativity or our glorious uniqueness.”

Gilda Radner

Making the Best of Your Situation

When you are dealing with cancer and physical and emotional challenges, some days are better than others. We hope you can find strength, hope and happiness – so you can enjoy the good days and live your life with cancer in the best way possible!

Tips to Simplify and Make Your Life Better

- Be nice to yourself/do nice things for yourself
- Order takeout - instead of cooking
- Ask a friend to drive you to your doctor appointments
- Take a trip to a place you have always wanted to go
- Ask a neighbor to pick up your kids from school
- If you need to buy a gift – order it online instead of going to the mall
- Make lists, so you don't forget anything
- Tell people you love them
- Appreciate the small things in life
- Laugh often and loud

As you deal with recurrent cancer, it's important to manage your stress so your mind and body can be as focused as possible on your treatment, quality of life and valuable time with family and friends.

Managing Stress

Dealing with the recurrence of a serious illness like ovarian cancer is extremely stressful. Everyone experiences stress differently, but some common responses to stress include headaches, jaw clenching, teeth grinding, neck or back ache, dizziness, pain, dry mouth, heartburn, panic attacks, constipation, loss of sexual desire, difficulty concentrating and making decisions, increased or decreased appetite, frequent crying spells, frustration and irritability.

Recognizing When You Are Stressed Out

Too much stress can lead to more serious health problems. Learn to recognize signs of stress in yourself and contact your healthcare professional if you experience the following on a regular basis:

- Denial about the disease and its effect on you and your family.
- Anger directed at your loved ones.
- Social withdrawal from friends and activities that once brought you pleasure.
- Anxiety about facing each day and the future.
- Depression and feeling unable to cope.
- Exhaustion making it impossible to complete necessary tasks of the day.
- Sleeplessness caused by constant concern and worry.
- Irritability that triggers negative responses and reactions in others.
- Lack of concentration making it difficult to perform usual daily tasks.
- Health problems which take their toll – mentally and physically.

Following are activities that many believe have stress-reducing effects:

- Breathing exercises
- Getting a massage
- Listening to relaxation tapes
- Taking a drive or spending time in nature
- Listening to relaxing music
- Reading a book or poetry
- Painting, drawing, playing an instrument
- Watching a comedic movie or TV show
- Playing with your dog or cat

For more information on stress reduction, visit www.stress.org.



Managing Anxiety

What is anxiety?

Anxiety is a vague feeling of uneasiness, unpleasant feelings or fear resulting from expecting some bad news or harm. Anxiety can happen to anyone, but women facing recurrent ovarian cancer may get anxious more easily than others. Anxiety and fear are common and normal feelings when coping with a life-threatening illness.

Recognizing Anxiety

People who have anxiety say they feel uneasy, tense, apprehensive, wary or agitated. They have a feeling of restlessness, uncertainty and are fearful or have a sense of dread or impending doom. People tremble, sweat, have rapid breathing, rapid heart rate or heart pounding in the chest. In addition, some people experience shakiness or difficulty falling asleep. Sometimes people become overly fearful and no longer cope well with day-to-day life.

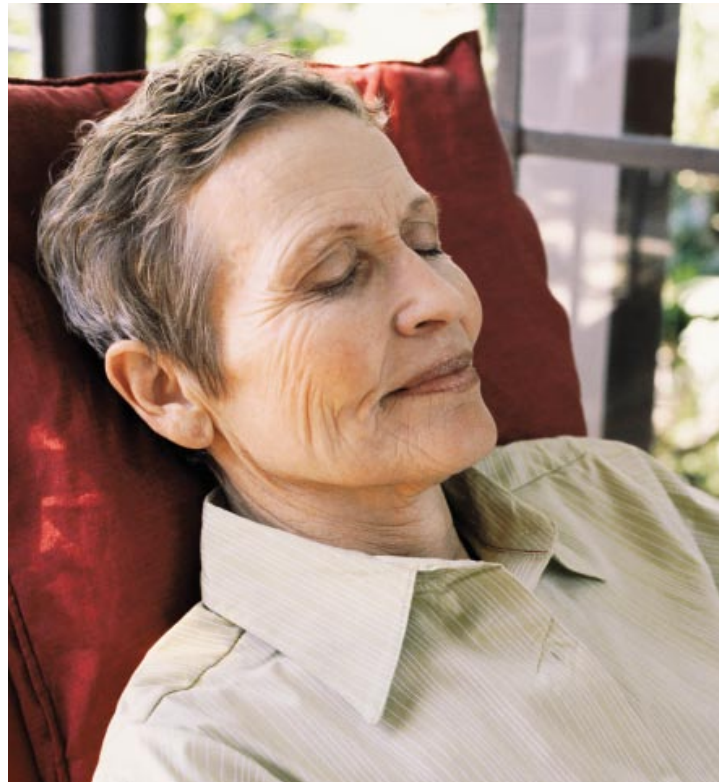
Coping with Anxiety

No two people experience anxiety in the same way. Here are some tips other people have found helpful:

- Try to identify what triggers your anxiety.
- List coping strategies that have helped in the past.
- Talk with others about your anxiety. Consider attending a support group.
- Increase pleasurable, distracting activities such as listening to favorite music.
- Use relaxation techniques such as controlled breathing or guided imagery (picture a pleasant scene in your mind).
- Be around others as much as possible, if this is relaxing.
- Use prayer or other types of spiritual support, such as meditation.
- Talk with your doctor or nurse about prescribing medicine to help reduce your anxiety.
- Express feelings and concerns to others.
- Limit your caffeine by decreasing your intake of coffee, tea, cola, highly-caffeinated beverages and chocolate.
- Ask your doctor for a counseling referral if these tips are not helpful.

Talking with Others about Your Anxiety

- Be open and honest about your feelings and concerns with your family members.
- Try to describe your feelings when you're experiencing them (racing thoughts, lump in your throat, nausea, shortness of breath, dizzy or scared).
- Ask your family members and friends how your anxiety is affecting them.



Call your doctor or nurse if you experience any of the following problems:

- **Panic attacks**
- **Problems with anxiety that last beyond 2 weeks**
- **Persistent fearfulness**
- **Shortness of breath that lasts beyond 2 weeks**
- **Shakiness, agitation or restlessness that lasts beyond 2 weeks**
- **Heart racing and beating hard in the chest**
- **Excessive sweating**
- **Persistent problems sleeping or getting to sleep**
- **No relief after trying suggestions**

Managing Depression

What is depression and sadness?

Depression is sadness that happens in response to an event or due to changes in your body chemistry. It is sadness that is greater than normal, lasts two weeks or more, and greatly impacts your daily life.

Recognizing Depression and Sadness

People describe depression as the darkest time in their life. Many people report crying spells, or problems with sleep (either sleeping all day or not enough sleep). Others describe problems with eating (too much or not enough), feeling hopeless, helpless, worthless or even feeling like they want to hurt themselves. People may have trouble experiencing any pleasure or interest in daily life and they may not want to talk to family or friends.

Depression is not the same as an occasional, short-lived period of sadness. In depression, these low feelings are severe, and stay for two or more weeks.

The Causes of Depression and Sadness

Depression can occur as a result of specific events, such as recurrent ovarian cancer. It also can be caused by medications, fatigue or from chemical changes in the brain. Generally, most people can cope with general short-term feelings of depression. Persistent depression (greater than two weeks) should be evaluated by a healthcare provider for possible counseling and/or medication.

Family Members and Friends Can Help

Ask them to:

- Stay with you (if you live alone) so that you are not by yourself.
- Talk with you about what you're going through.
- Do fun things with you.
- Sit with you during difficult times. Sometimes just having someone there with you is enough.
- Help you with your daily needs until you are able to care for these on your own.
- Help you with relaxation exercises.
- Help you with situations or chores that you find stressful, such as going to your doctor visits, writing out bills or helping with household chores.
- Notify your doctor or nurse for you when needed.

Coping with Depression and Sadness

Every person uses different approaches when they are depressed and sad.

Following are tips other people have found helpful:

- Try controlled breathing and relaxation exercises; these help release mood-enhancing substances from the brain.
- Express your feelings through journal writing or creative expression (dance, cooking, exercise, painting or music).
- Avoid alcohol consumption; it can make you feel more depressed.
- Try to get enough sleep at night; avoid napping during the day.
- Go outdoors and walk in natural settings, such as a garden or park.
- Try meditation or massage.
- Try to identify something that brings you pleasure every day.
- Be with other people as much as possible, if this helps you relax.
- Participate in regular, routine exercise (walking for 20 minutes, 3-5 times per week, for example). Exercise has been shown to improve mood and well being.
- Make an appointment with your doctor and tell him/her exactly how you feel and that you need help.
- Make a list of all the medications you take; show this to your doctor or nurse. Some medicines may have to be stopped or changed.
- Join a support group. This can help relieve the isolation that is often felt by those who are depressed.
- Make an appointment with a counselor, spiritual advisor or psychologist.
- If medicines have been ordered for your depression, take them as directed.



Depression Checklist

Call your doctor or nurse if you experience any of the following for more than two weeks:

- Depressed mood every day for most of the day
- Very little interest or pleasure in most activities nearly every day for most of the day
- Noticeable weight loss or weight gain - or a major change in appetite
- Sleep disturbance: not being able to fall sleep, waking early or being very sleepy
- Feeling agitated or feeling slowed-down
- Feeling excessively tired or lacking in energy
- Feeling worthless or guilty
- Feeling unable to concentrate or make decisions
- Feelings of hopelessness and/or helplessness

If you ever have feelings (or actions) that you want to hurt or kill yourself or others, call your doctor immediately, or call a national suicide hotline at:

www.hopeline.com

1-800-SUICIDE (1-800-784-2433)

www.suicidepreventionlifeline.org

1-800-273-TALK (1-800-273-8255)

Making the Most of Sexuality and Intimacy

When coping with recurrent cancer, sex and intimacy may be the last thing on some women's minds due to cancer side effects or the stress of dealing with recurrent cancer. For others, the closeness that sexuality and intimacy can bring may be just what she desires.

Women with ovarian cancer often have to learn to cope with serious, long-term sexual problems that can include decreased libido, vaginal dryness and pain during intercourse. These problems can arise from multiple causes, including surgical or treatment-related menopause, disturbed body image and increased psychological distress.

It may be awkward to bring up, however, it is extremely important for you and your partner to communicate openly with each other about sexuality and intimacy during this difficult time. It is important to discuss your desires and fears and talk about ways to satisfy these needs in a way that is comfortable for both of you. Remember to be patient, stay connected and only do what you are comfortable doing.

Communicate – Talk to your partner about your needs and limits. Address each other's fears.

Explore Non-Sexual Intimacy – Hugging, cuddling, kissing and holding hands can be a satisfying addition or alternative to sex.

Rest and Plan – Rest before and after sexual activity and plan sexual activity during times when you think you have the most energy.

Use Lubricants – Hormonal changes can result in your vagina being drier than usual. Water-soluble lubricants can help.

Talk to Someone – In some cases, it's helpful for couples to speak to a counselor or therapist to help you deal with emotional issues and sexual problems associated with your cancer treatment and recovery. The American Association of Sex Educators, Counselors, and Therapists (www.aasect.org) can assist with identifying a credentialed sex therapy professional.

There are several excellent self-help books on the topic of sexual function for women with ovarian cancer.

Ovarian Cancer: Sexuality and Intimacy is available for free by contacting The National Ovarian Cancer Coalition at 1-888-OVARIAN or www.ovarian.org.

Sexuality & Cancer for the Woman Who Has Cancer and Her Partner is available for free from the American Cancer Society by calling 1-800-ACS-2345.

Sexuality and Fertility After Cancer by Leslie R. Schover, Ph.D. (John Wiley & Sons, 1997) also is an excellent resource.



End Of Life Concerns

Women are living longer thanks to new treatments and your treatment team will work with you to plan a sequence of treatments to fight your cancer. However, a recurrence of ovarian cancer usually generates many concerns about the end of life.

Some women worry about dying at the onset of their diagnosis. Others don't begin thinking about it until they have taken multiple chemotherapy regimens. What is important is that you think about this issue when the time is right for you.

While end-of life issues are difficult to discuss with loved ones, it is important to do so. Usually, once the subject is discussed, everyone feels a great sense of relief.



Making Your Wishes Known

Advance Medical Directive

An Advance Directive is a set of instructions you give for your future medical care. These instructions would be followed when and if you were unable to make decisions for yourself, such as when you become too ill to communicate or are unconscious. There are several options for these instructions.

1) Living Will

A living will is a document that explains your wishes for medical care when you cannot make your own decisions. It is important to have this discussion with your family members and make a living will while you are healthy, so no one has to make a tough decision for you when you cannot.

2) Surrogate Decision Maker

You also can identify and name someone you trust to make medical decisions for you. This is called the durable healthcare power of attorney or healthcare proxy. Depending upon where you live, this person may be able to make medical decisions for you at any time you are unable to do so. In other states, this person can only make decisions for the patient at the end of her life.

It is important to create these documents now. You can revise or modify them at any time. If you think of an Advance Directive as an ongoing dialogue with your loved ones and healthcare team, you will be able to change it as needed to fit with what is going on in your life. By creating this document, you can be assured that your wishes will be met and relieve your family of the burden of making these difficult decisions for you.

Do Not Resuscitate

A Do Not Resuscitate or DNR order can be part of your Advance Directive. In this situation, you request that you not be put on a breathing machine if you stop breathing and that you do not receive cardiopulmonary resuscitation (CPR) if your heart were to stop beating. Once this decision is made, your doctor places a DNR order in your chart. This order usually must be renewed on subsequent hospitalizations.

People often are reluctant to discuss this issue with their physician as they feel DNR means they will no longer receive appropriate medical care. This is not the case. The DNR only means that when you die, when your heart stops beating and/or you stop breathing, extraordinary measures such as CPR and being placed on a ventilator (breathing machine) will not be done. Any and all other measures to sustain life will be continued.

As with the Advance Directive, a DNR order gives you control in what could be a very difficult situation for you and your family. It ensures that your wishes are respected.

Considering Hospice

Once you decide that you no longer wish to receive chemotherapy or other therapies to treat the cancer, focus shifts to making sure that you are as comfortable as possible and that symptoms such as nausea or pain are effectively managed. Quality of life is the highest priority.

Hospice care focuses on meeting physical, emotional and spiritual needs, while fostering the highest quality of life possible. Hospice care is provided by a specially-trained team that includes physicians, nurses, social workers, pastoral care workers and volunteers who are experts in end-of-life care. Hospice providers have experts in medical care, emotional support and spiritual care.

Hospice can take place in a special hospice facility, a hospital or in the home. The goal of hospice is to support you and keep you comfortable during this time. In addition to helping you, hospice also provides a great service to your loved ones.

If and when you are ready to explore hospice, speak with your doctor, nurse or someone from your cancer center. They can refer you to hospice care in your community.

“I wanted a perfect ending. Now I’ve learned, the hard way, that some poems don’t rhyme, and some stories don’t have a clear beginning, middle and end. Life is about not knowing, having to change, taking the moment and making the best of it, without knowing what’s going to happen next.”

Gilda Radner

Guiding Words

Recurrent ovarian cancer is an unpredictable and complex journey of the body, mind, heart and human spirit.

We hope that the knowledge and understanding you may have gained by reading this guide gives you strength to face recurrent ovarian cancer.

This guide provides a lot of information and we hope is a helpful reference. But remember, this is only a place to start. Ask questions. Communicate openly and often with your doctors and nurses. Search for reliable information on the Internet. If you'd like to connect with other ovarian cancer survivors and their families, contact NOCC to be connected with a local Chapter.

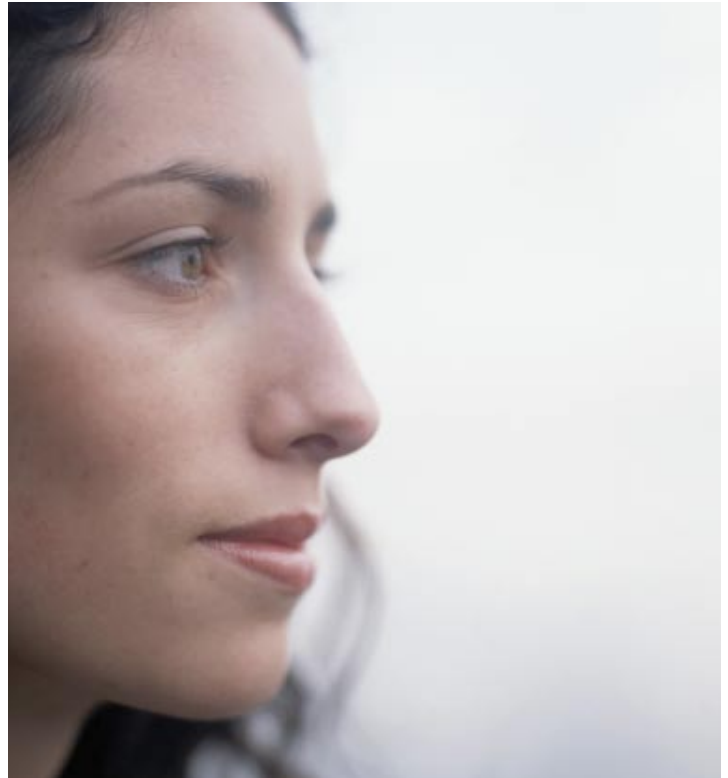
As always, if you have any questions, feel free to contact us at 1-888-OVARIAN or to visit our website, www.ovarian.org. If we can't answer your question, we will direct you to someone who may be able to help.

Our parting words to you...

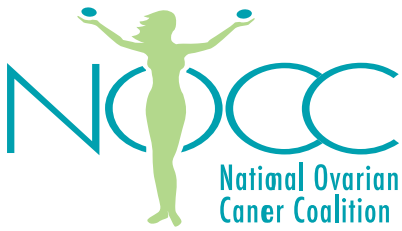
Be kind to yourself. Treasure every day. Live life to the fullest.

Sincerely,

The National Ovarian Cancer Coalition



Laughing out loud I will create my
own destiny. Singing in the wind
I will forge the river and be louder
than the storm that howls about me.



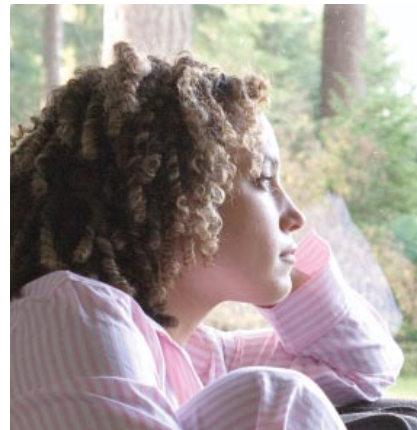
National Ovarian Cancer Coalition, Inc.

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Ovarian Cancer... *It Whispers, So Listen!*

Mission Statement

The National Ovarian Cancer Coalition's mission is to raise awareness and promote education about ovarian cancer. The Coalition is committed to improving the survival rate and quality of life for women with ovarian cancer.