FOR WOMEN WITH RECURRENT DISEASE

"a ribbon we use to wrap around those needing comfort"

™

NATIONAL OVARIAN CANCER COALITION
ABOUT THE NATIONAL OVARIAN CANCER COALITION®

Since its inception in 1991, the National Ovarian Cancer Coalition (NOCC) has been committed to raising awareness of ovarian cancer in communities across the country through education and support. As the first and only national ovarian cancer organization with a network of local chapters located throughout the United States, the NOCC has established itself as the leading advocate for patients and families coping with ovarian cancer. The NOCC works to advance its mission through national awareness and survivorship programs, a comprehensive website, a toll-free information line, peer support, professional education, and publications like this one.

The NOCC’s national programs include:

• The Take Early Action & Live (TEAL) initiative provides education and increases awareness of ovarian cancer.

• Faces of Hope provides up-to-date information, hope, and support to women with ovarian cancer, their families, friends and loved ones.

• The Together in TEAL® - Ending Ovarian Cancer raises awareness, celebrates survivors, and remembers those lost to the disease.

• NOCC CancerConnect provides an online, HIPAA compliant platform to find peer-to-peer support, share experiences, and build community.

• The NOCC Research in Action® initiative provides critical funding to help support the progress of new treatment, and ultimately a cure, while supporting research initiatives such as clinical trials that save and extend lives today.

For more information about the NOCC, visit ovarian.org or call 1-888-OVARIAN (1-888-682-7426).
INTRODUCTION: FROM US TO YOU

FINDING OUT THAT YOU HAVE OVARIAN CANCER IS A SHOCK.
But finding out that you’ve had a relapse can be devastating. You might even feel more depressed than you did when you were originally diagnosed, and think to yourself, “How could this be happening to me? Haven’t I been through enough already?” But recurrences happen. Months or years following treatment, many women are again diagnosed with active ovarian cancer, while some remain cancer-free. Still others go in and out of remission for months, or even years.

If your cancer has recurred, we know this is a challenging time for you and your family. 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 get through your initial diagnosis. Try to stay positive, empower yourself with information, channel your strength, and, most of all, remain hopeful. There are effective medical treatments for recurrent cancer. In fact, ovarian cancer is now often thought of as a chronic disease, one that you can live with for many years with a good quality of life.

We, at the National Ovarian Cancer Coalition (NOCC), hope this booklet will help you make informed decisions about your treatment and be proactive in managing your health. It is not meant to take the place of direct communication with your treatment team. It is another tool for you to use as you face your recurrence. We have tried to help by including quotations shared by other women who have dealt with recurrent ovarian cancer. The more you know, the easier it will be to make decisions that are best for you.

In addition to this booklet, there are other ways to find support through the NOCC. We encourage you to reach out to your local NOCC Chapter to find support groups in your area. Additionally, you will find helpful support through our HIPAA compliant online sharing community, NOCC CancerConnect, by going to nocccommunity.ovarian.org. Follow us through Facebook, Instagram, and Twitter for inspiring messaging, important research information, and more. You can also call 1-888-OVARIAN or visit ovarian.org for more helpful resources.

With support and encouragement,
NATIONAL OVARIAN CANCER COALITION
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WHEN OVARIAN CANCER RETURNS

• Understanding Recurrence
• Determining Whether You’ve Had a Recurrence
• What is the Meaning of “Time to Recurrence”?
• Platinum-Sensitive Cancer
• Platinum-Resistant Cancer
• Questions about Treatment Options to Ask Your Medical Provider
• How to Take Charge of Your Recurrent Disease
• Genetic Testing
• Dealing with Your Emotions
• Enlisting the Support of Others
UNDERSTANDING RECURRENCE
For anyone who has had ovarian cancer, the end of treatment is not the end of fear. For months, if not years, afterwards, you worry that your cancer is back every time you feel the slightest ache or pain. No matter how long it’s been since you finished treatment, there are certain times (checkup appointments, blood tests, the moment you read something scary about cancer), when you worry more about a recurrence (known as “recurrent cancer”). Many women have these feelings.

Although most ovarian cancers respond well to initial chemotherapies, the disease frequently recurs. A recurrent cancer starts with cancer cells that the first treatment didn’t fully remove or destroy. It doesn’t mean that your doctor did anything wrong. Some cells might have been too small to be detected.

If your cancer does return, it’s important to remember that no matter what, you and your healthcare team now know more about ovarian cancer than you did when you were initially diagnosed. New drugs or treatments may help you with your treatment or in managing side effects. You, your doctor, and your healthcare team will focus on controlling the spread of cancer by using the most effective treatments available. Researchers are actively developing strategies to prolong remissions. In fact, cancer today is often considered a chronic disease, one which many people live with for many years.

DETERMINING WHETHER YOU’VE HAD A RECURRENCE
If you underwent surgery or chemotherapy, your gynecologic oncologist has kept track of your health status through frequent pelvic exams and the CA-125 blood test. However, not all women are followed by a gynecologic oncologist, or track their CA-125 level, since there is varied opinion in the medical community as to whether monitoring CA-125 levels improves overall survival.

A CA-125 level of 35 or under is considered in the “normal” range. A decreasing level after therapy generally indicates that treatment has been effective, while an increasing level indicates tumor recurrence. Test results can vary, so small changes from one test to the next are usually not considered significant. However, if the CA-125 rises consistently for a few months, particularly if there is a doubling from the lowest value, you may no longer be considered to be in remission. It may be the case, as well, that a CA-125 level in the “normal” range may signal a recurrence. For this reason, the use of CA-125 parameters as an indicator should be discussed with your physician with regard to what would signal a concern.

WHAT DOES “TIME TO RECURRENCE” MEAN?
An important concept about ovarian cancer to understand is “time to recurrence.” This refers to the time between completing your initial course of 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.
CHAPTER 1

PLATINUM-SENSITIVE CANCER
Many clinicians and studies are focusing on less than 6 months, within 6 to 12 months, and beyond 12 months as the dividing lines in platinum response. Generally, if ovarian cancer returns 6 or more months after the first treatment with a platinum-containing chemotherapy regimen, 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 when initially diagnosed.

Women with platinum-sensitive disease have the greatest number of potential options for second-line therapy.

PLATINUM-RESISTANT CANCER
If ovarian cancer does not respond to primary or initial treatment with a platinum agent (such as cisplatin or carboplatin), or if the cancer returns less than 6 months after completing primary chemotherapy, the cancer is considered platinum-resistant.

Women who have been diagnosed with 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 may be used to avert the cancer.

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 treatment.

It is important for women to be encouraged to participate in clinical trials that evaluate the benefit of new treatments. This is true in the case of either platinum-resistant or platinum-sensitive cancer. If ovarian cancer does not respond to platinum treatment during upfront treatment, this is platinum refractory disease, and prognosis is poor. If ovarian cancer recurs within 6 months of completing platinum treatment, the cancer is considered platinum resistant.

PLATINUM-SENSITIVE VS. PLATINUM-RESISTANT

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<th>PLATINUM-SENSITIVE</th>
<th>PLATINUM-RESISTANT</th>
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<tr>
<td>RECURRENCE</td>
<td>6 or more months of remission</td>
<td>Less than 6 months after initial treatment</td>
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<tr>
<td>RESPONSIVENESS</td>
<td>Responsive to platinum-based therapy</td>
<td>Not responsive to platinum-based therapy</td>
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<tr>
<td>TREATMENT</td>
<td>Often treated with more than one chemotherapy agent plus or minus bevacizumab</td>
<td>Usually treated with non-platinum single agent or combination of non-platinum single agent</td>
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TAKE CHARGE WITH RECURRENT DISEASE
It is difficult to learn you have recurrent cancer, however, the earlier you accept the diagnosis, the sooner 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.

EMPOWERING 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 websites.

GENETIC TESTING
If you have not already undergone genetic counseling and testing to identify potential genetic predispositions for ovarian cancer, now is the time to consider this. Current Society of Gynecologic Oncology (SGO) guidelines state that all women with epithelial ovarian cancer should be offered genetic counseling and testing.

Approximately 15-20% of women with ovarian cancer have a genetic predisposition, most commonly in the BRCA1 or BRCA2 genes, but other genetic mutations also increase the risk of ovarian cancer. If you do not have a genetic predisposition to ovarian cancer, your tumor may be tested to see if you have a somatic BRCA mutation (a change in the DNA in your tumor that was not inherited), as you may also benefit from a PARP inhibitor.

TUMOR TESTING
Tumor testing analyzes the genes and biomarkers within the tumor. Mutations in genes in the tumor may have been inherited and are present in every cell in the body (including the cancer cells), or the mutations may have arisen just in the cancer cells. It’s possible, for example, to test negative for a BRCA mutation in a genetic test that looks at genes that have been inherited, but to test positive for a mutation in a profile of the tumor itself.

Regardless of the origin of the mutations and biomarkers in the tumor, testing the tumor gives information about what may be driving the cancer and therefore what type of treatment you may want to consider at this stage. Targeted therapies are a type of treatment that can act on specific mutations within the cancer cells. One class of targeted therapies that can be considered based on tumor testing is PARP inhibitors, a group of pharmacological inhibitors of the enzyme poly ADP ribose polymerase. Other biomarkers, such as microsatellite instability and tumor mutational burden, can predict response to immunotherapies, which harness the body’s own immune system to attack cancer cells.

Tumor testing can also reveal mutations and biomarkers that could point you toward a clinical trial, which is another option to receive treatment while participating in the development of new therapies. Whether tumor testing identifies options for FDA-approved targeted therapies for ovarian cancer, other approved therapies, or clinical trials, testing the tumor is a way for you to benefit from precision medicine by finding the treatment options best matched to your specific cancer.
If you are diagnosed with recurrent cancer, your doctor will develop a treatment plan. Planning treatment is quite similar to planning treatment for your primary cancer.

Here are some questions to ask:

**KEY CONSIDERATIONS**
- What are my treatment options? Is surgery an option?
- Which do you think would be best for me?
- Is the treatment the same or different from my last chemotherapy?
- How long will I be on this treatment?
- How soon should treatment be started?
- How successful is the treatment that you recommend for me?

**TOXICITY**
- Will I have side effects? If so, are they different than those I am already experiencing? How long will they last?
- How can I manage the side effects?
- Will I have to stay in the hospital?

**INVESTIGATIONAL THERAPIES**
- Am I a candidate for a clinical trial?
- Should I consider a clinical trial?
- Why is the clinical trial being done?
- How will I benefit from a clinical trial?
- What are the risks of participating in a clinical trial?
- Will I have to pay any costs in a clinical trial?
- What will I be expected to do if I participate in a clinical trial?

**QUALITY OF LIFE**
- What are the most important quality of life issues for me?
- What are the goals of the treatment?
Why should you have genetic testing at the time of recurrence?

- If you have a BRCA1 or BRCA2 mutation or HDR mutation, you may benefit from treatment with targeted therapies, such as PARP inhibitors.
- You may be eligible for clinical trials of new therapies that target BRCA and other genetic mutations.
- Knowledge about your genetic risk can help you to educate and protect your family members. If you have a genetic mutation, your relatives, both female and male, can also be tested. Knowledge about genetic risk can empower them to reduce their own risk for cancer. Ongoing research is identifying the best screening, lifestyle, medication, and surgical approaches to protect individuals who are at high risk for developing cancer. KNOWLEDGE IS POWER!

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. You may find it helpful to spend time with a spiritual advisor to discuss your feelings.

Sometimes, as women focus on treating their 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 possible treatment plan.

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 information about depression and anxiety, visit NOCC’s website at www.ovarian.org.

ENLISTING SUPPORT
Family, friends and coworkers will want to help during this difficult time. Learn how to accept the support and encouragement of your loved ones. It may be also helpful to consider seeking spiritual support.
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 time alone, 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.

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**ALICIA, MARYLAND**

“Having Ovarian Cancer twice changed my life by causing me to slow down and enjoy every moment in life. As a survivor friend once told me, “Of course, it goes without saying that your life has changed forever but not necessarily the way you think. There are just as many beautiful aspects to this as there are scary ones.” Look for the beauty in each and every day because it is there and will give you strength to keep going.”
UNDERSTANDING TREATMENT OPTIONS

• When Should I Begin Treatment?
• Treatment Based on Rising CA-125
• Developing an Individualized Treatment Plan
• When Supportive Care Makes Sense
• Understanding Clinical Trials
Once you have been diagnosed with recurrent cancer, there are many important treatment-related issues to consider: When should treatment begin? How will the medications used affect my quality of life? Should I participate in a clinical trial? You may also want to consider getting a second opinion to learn about other possible treatment options.

WHEN SHOULD I BEGIN TREATMENT (NOW OR LATER)?
Depending on whether your 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 you have evidence of disease based on a physical exam or radiographic evidence (e.g. CT scan), or are 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 treatments for possible recurrence based on increasing CA-125 levels alone. While increases in CA-125 can cause alarm and concern among many women, they do not always signify a relapse. This is because other conditions can cause transient increases in CA-125 levels. These conditions may include endometriosis, uterine fibroids, pancreatitis, pelvic inflammatory disease, diverticular disease, and cirrhosis. Many conditions, other than cancer, can result in an elevated CA125.

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 person and every situation is unique. Ask your doctor about his/her view with regard to CA-125 and your case.
As you consider treatment for recurrent ovarian cancer, it is very important that you discuss your goals and your doctor’s goals for treatment. For most women, the most important goal is to keep 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.

DEVELOPING AN INDIVIDUALIZED TREATMENT PLAN

Once you and your doctor have agreed to begin treating your 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 can discuss as you make important treatment decisions:

• How long after your initial treatment did your disease recur?
• What are the genetic considerations, if any?
• 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?
• Is surgery an option?
• Are there any clinical trials in which I am eligible to participate?
• Will participating in a trial exclude me from future treatments/trials in the future?
• Are there life events that need to be planned around (ie: weddings, trips)?

MARY BETH, NEW YORK

“Recurrence was harder to accept than my original diagnosis but once I caught my breath, I realized that the most important thing to do is to trust in myself, and my medical and support teams. With the new PARP inhibitors recently approved for recurrent ovarian cancer, my chances of extending my life are better than they ever were. An attitude of gratitude is my mantra and it has served me well for 4 years and counting.”
Diane, Arizona

“I am loving life at 68 years old and 4 years 3 months post my last chemo for ovarian cancer 3C. I had an excellent surgeon & my 3rd oncologist & my naturopath got me through the chemo. I thank God for answering the prayers of my family, friends, church and my own to extend my life.”

Optimizing Quality of Life
When making treatment decisions, it is important to weigh the possible benefits of treatment (e.g. remission, longer survival, etc.) with risks of treatment side effects that reduce your quality of life. Be sure to discuss issues related to quality of life with your care team.

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 located, and how much is present. If ovarian cancer 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 completely.

Treatment for Platinum-Sensitive Ovarian Cancer
If you experience a recurrence more than 6 months after completing your initial therapy, you are considered platinum-sensitive, and you have a number of potential options for second-line chemotherapy. 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 may also recommend bevacizumab in combination with chemotherapy, followed by bevacizumab maintenance, due to recent evidence. Another alternative is a PARP inhibitor for maintenance after a complete or partial response to chemotherapy for platinum-sensitive disease.

Treatment with Platinum-Resistant Cancer
If you have platinum-resistant cancer, it is unlikely that you will benefit from re-treatment with a platinum-based regimen. However, there are several alternative chemotherapy drugs that can be used to treat recurrence.
Most doctors do not recommend combining more than one chemotherapy 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 may be more toxic to a woman’s body. There may be a role for biologic avenues, such as bevacizumab.

Some recurrent cancers respond to treatment. Other 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 during a treatment, and the treatment is well tolerated, most doctors will recommend continuing that treatment until the cancer begins to grow again. Sometimes, the cancer does not respond to the treatment and grows, which is called “progressive disease.”

WHEN SUPPORTIVE CARE MAKES SENSE
Supportive or palliative care means that an emphasis is placed on treating or preventing symptoms caused by the cancer or its treatment. The overarching goal is to relieve physical and emotional suffering, and to improve the quality of a woman’s life. Palliative and supportive care can and should be a part of your treatment for recurrent ovarian cancer, so that you can maintain the highest quality of life possible.

At one time, people thought of palliative care as a way of comforting those who were dying of cancer. But today, this care is offered to all advanced cancer patients, beginning when you are diagnosed.

Supportive care and symptom management should be occurring whether you are receiving chemotherapy or have stopped active chemotherapy treatment. In particular, if you have decided to stop treatment for any reason, such as if the side effects of chemotherapy become too difficult, the focus of care will shift to symptom management and supportive care.

Common symptoms that are treated by palliative care include:
- Pain
- Difficulty breathing
- Loss of appetite and weight loss
- Fatigue
- Weakness
- Sleep problem
- Depression and anxiety
- Nausea and vomiting
- Constipation

UNDERSTANDING CLINICAL TRIALS
Clinical trials are 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 United States. To ensure the reliability of the data and the safety of participating patients, all clinical trials evaluating medications are conducted under the strict guidelines of the U.S. Food and Drug Administration (FDA).
Questions to Ask When Considering a Clinical Trial

• What is the purpose of the study?
• Who is conducting the trial?
• What is likely to happen to me if I do or don’t participate?
• Why do researchers believe the treatment may be effective?
• What type of treatment or tests will I have to take?
• How long does the trial last?
• How might the trial affect my daily life?
• Will I have to be hospitalized? If so, for how long?
• Will my insurance cover the costs?
• Will I be reimbursed for any other expenses?
• Will my doctor be able to stay involved in my care?
• Is long-term follow-up care part of the study?
• Will participation in a trial exclude me from future treatments/future trials?

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

There are different phases of clinical trials:

In Phase I trials, researchers test an experimental drug or treatment to evaluate its safety, determine a safe dosage range, and identify side effects with regard to all types of cancer.

In Phase II trials, the experimental drug or treatment is given to a larger group of people to see if it is effective and to further evaluate its safety with regard to a particular type of cancer.

In Phase III trials, the experimental therapy is given to large groups of people to confirm its effectiveness and benefits, and to monitor possible adverse reactions. It is compared to the therapy that is considered standard of care or the gold standard, in order to see which has better outcomes and fewer side effects.

In Phase IV trials, studies are done after the drug or treatment has been approved for consumer sale. Pharmaceutical companies determine additional information including: the drug’s long-term effectiveness, how it compares to other drugs already on the market, and its cost-effectiveness.

IS A CLINICAL TRIAL 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. On balance, clinical trials can provide treatment options that you might not otherwise have the opportunity to receive. If you participate in a clinical trial, you will be closely monitored to see if you are responding to the treatment. If the treatment or therapy is not effective, you will be taken off the study.
Patients who have participated in clinical trials have been shown to do better than patients who do not participate. The advances that have been made in the care of women with ovarian cancer are the direct result of prior clinical trials. Many women are motivated by the potential that clinical trial participation has to benefit the next generation of women with ovarian cancer.

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 provided with treatment options that would otherwise not be offered to them. It is important to remember that participating in a clinical trial includes careful monitoring of the patient and potential side effects.

• Another benefit is that you obtain expert medical care at leading healthcare facilities during the trial.

• Participating in a clinical trial may include extra blood draws, imaging, or additional trips to the study site.

• If you decide to enter a clinical trial, you will have the opportunity to withdraw at any time if you no longer want to be part of the study. In addition, the investigator may choose to remove you from the study if there is concern that you are experiencing some difficulty participating in some way, or may not be responding to the treatment.
RESOURCES

CLINICAL TRIAL RESOURCES: WHERE DO I BEGIN?
Following are some valuable resources that will help you learn more about clinical trials that might be appropriate for you.

NATIONAL OVARIAN CANCER COALITION, INC.
888-OVARIAN (888-682-7426)
ovarian.org

CANCER TRIALS SUPPORT UNIT
888-823-5923
ctsu.org
The Cancer Trials Support Unit is a project sponsored by the National Cancer Institute (NCI) to make NCI-supported Phase III cancer treatment trials available to physicians nationwide.

CLINICALTRIALS.GOV
A service of the NIH, this is a registry of federally and privately supported clinical trials conducted in the U.S. and around the world.

COALITION OF CANCER COOPERATIVE GROUPS
877-227-8451
cancertrialshelp.org
The Coalition of Cancer Cooperative Groups is composed of cancer clinical trial specialists and offers a variety of programs and information for cancer patients, healthcare providers, and patient advocates. These programs are designed to increase awareness and participation in clinical trials.

EMERGINGMED
877-601-8601
emergingmed.com
This site allows you to create a profile that can then be matched to clinical trials.

NATIONAL CANCER INSTITUTE CLINICAL TRIALS REFERRAL OFFICE
888-NCI-1937 (888-624-1937)
ccr.cancer.gov/clinical-trials
This is the cancer-specific arm of the NIH; it offers comprehensive information about cancer clinical trials.
MANAGING YOUR TREATMENT

- Managing Side Effects
- Complementary & Alternative Treatments
You probably know quite a bit about ways to manage the side effects of ovarian cancer treatment. If so, some of this section may be more of a review for you. Each chemotherapy drug has potential side effects, and these can affect people differently.

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 the 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.

Pay close attention to how you feel and report any side effects to your doctor or nurse. The earlier 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**

Fatigue is different from just feeling tired. If you feel physically, mentally and/or emotionally 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, going to work, 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, treatment typically consists of a blood transfusion. Some patients may require epogen shots. If anemia is not the cause of the fatigue, treatment options can include Ritalin or ginseng.

**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. Conserve energy whenever possible (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 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.

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"As a filmmaker and an ovarian cancer survivor, who has experienced two recurrences, I have embraced living in the creative, inspiring spaces between the chaos. And I’ve learned to live fully and without regret.”
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 AND PALLIATIVE CARE
Cancer pain can occur as a result of tests, surgery, chemotherapy, radiation therapy, hormonal therapy, or from pressure from the tumor. However, 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 that 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 medications 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.

Don’t be afraid to ask for pain medications if you need them. The drugs will help you stay as comfortable as possible. Sometimes, though, people are afraid to take pain medicine because they are afraid they will get addicted to it. Similar fears also prompt family members to encourage loved ones to “hold off” between doses. But people with cancer hardly ever get addicted to these drugs.

Helpful tips for controlling your pain include:

- Be sure to take your pain medication 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 and alternative medicine (CAM) therapies, such as guided-imagery exercises, acupuncture, and massage therapy, can be very helpful in addition to your pain medications.

• You may want to keep a pain diary to help you explain pain to your doctor. If you do this, write down the time of day you experienced your pain, what you were doing when you had the pain, what it felt like, and where in the body you felt it the most.

• 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
If you have to undergo chemotherapy again, the chance of losing your hair again is very real. Some 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 hairnet 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. Often times a prescription can assist with insurance coverage.

“Look Good…Feel Better” is a national program dedicated to improving the self-esteem and confidence of anyone undergoing treatment for cancer. It offers complimentary “group, individual, and self-help” beauty sessions to help you with hair, makeup, and nail care.

For information, call 1-800-395-LOOK or go to www.lookgoodfeelbetter.org.
• 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, your hair may still be fragile and dry. Treat it gently. Use mild shampoos, a soft hairbrush and avoid dyes, hair sprays and permanents.

NAUSEA AND VOMITING
Nausea is feeling sick to your stomach. Vomiting is throwing up. Both can be a problem for women dealing with recurrent cancer. Nausea and vomiting are best managed by using several approaches simultaneously, tailored to the type of nausea you are experiencing. Approaches include medications, watching what you eat and drink, and CAM therapies, such as relaxation, guided imagery, or acupuncture.

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 and alternative medicine (CAM) therapies.

Acute nausea and vomiting, which occur within 24 hours of chemotherapy treatment, are generally managed with anti-emetic medication. If the chemotherapy regimen is associated with significant 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 the pill. This regular dosing is done to prevent nausea from occurring.

You may find these suggestions helpful:
• Relax before treatments: Sometimes nerves or the thought of treatment can trigger an upset stomach.
• Avoid greasy, high-fat foods: Stay away from fried foods, potato chips, spicy foods, or those with strong smells. These may make nausea and vomiting worse.
• Minimizing the intake of milk products may prove helpful.
• 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.

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 changes in your diet, pain medication, anti-nausea medication, and/or inactivity. If you experience severe stomach pain, cramping, or diarrhea for more than a day, call your doctor immediately.

TIMELY TIPS

MANAGING GASTROINTESTINAL ISSUES

AVOIDING/ALLEVIATING DIARRHEA

• Drink plenty of fluids - Water, weak tea, or clear broth. Mix grape, apple, or cranberry juice with water for better tolerability.
• Emphasize food associated with what is known as the BRATT diet, which includes foods easy on the stomach, such as bread, rice, applesauce, tea and toast.
• Avoid greasy foods, bran, raw fruits and vegetables, high-fat foods, candies, preserves, and nuts.
• Add foods high in potassium. This includes bananas, potatoes, and apricots.
• Eat small meals, often.
• Use reduced-lactose products, and avoid milk or dairy 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.
• Reintroduce foods, one at a time, to see whether they cause an increase in diarrhea.

AVOIDING/ALLEVIATING CONSTIPATION

• Drink plenty of fluids (8-10 glasses/day) - Non-caffeinated and warm fluids can help stimulate your system.
• 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. And add a Fiber Laxative to Your Diet.
• Talk to your doctor before using suppositories or enemas (laxatives other than fiber, or stool softeners) - Taking the wrong treatment can make your condition worse. Some of these treatments should not be used when your white blood counts are low.
SLEEP PROBLEMS
It’s not unusual to have trouble sleeping if you are in pain, under a great deal of stress, feeling ill, or are in the hospital. You might have trouble falling asleep, have trouble staying asleep, wake up earlier than usual, or only sleep for brief periods at a time.

If you are having sleep problems, here are some simple tips to try:
• Make sure your room is dark, cool, and quiet.
• Dress in loose, soft clothing.
• Go to the bathroom before bed.
• Avoid drinking too many liquids in the evening.
• Eat a light, high-protein snack two hours before bedtime (such as some sliced chicken or turkey, or half a peanut butter sandwich).
• Keep regular sleep hours.
• Talk with your healthcare team about drugs to help you sleep and manage your pain.

MAKING THE MOST OF SEXUALITY AND INTIMACY
When coping with recurrent cancer, sex and intimacy may be the last thing on your mind, due to cancer side effects or the stress of dealing with recurrent disease. Feeling self-conscious about the way you look, or feeling stressed out by your diagnosis of recurrent cancer and your treatment may also affect your sexuality. For some women, though, the closeness that sexuality and intimacy can bring may be just what they want.

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, distorted 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. An important part of recovery is to try resuming sex when you feel ready.

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 will have the most energy.

USE LUBRICANTS
Hormonal changes can result in your vagina being drier than usual. Water-soluble, unscented lubricants can help.

TALK TO SOMEONE
In some cases, it’s helpful to speak to a counselor or therapist to help you deal with emotional issues and sexual problems associated with your treatment and recovery. The American Association of Sexuality Educators Counselors and Therapists (www.aasect.org) can assist with identifying a credentialed sex therapy professional in your area.

There are also several excellent self-help resources on the topic of sexual function for women with ovarian cancer. They are as follow:

- **Sexuality for the Woman With Cancer** is available for free from the American Cancer Society by calling 1-800-227-2345. Also available for free from ACS is Couples Confronting Cancer: Keeping Your Relationship Strong.
- **Sexuality and Fertility After Cancer** by Leslie R. Schover, Ph.D. (John Wiley & Sons, 1997) also is an excellent resource.

“I asked my husband to be patient. The last thing on my mind right now is sex.”

ANONYMOUS

MOUTH AND THROAT PROBLEMS (MUCOSITIS)
Chemotherapy drugs can affect the lining of your mouth, throat, and tongue and 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:

- Choosing soft foods, such as milkshakes, 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), or alcohol-free mouthwashes 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 Gelcair to coat the inside of your mouth.
- Talk to your doctor about systemic pain medication for relief, if needed.

**FIGHTING INFECTION**

As you learned when you went through your initial treatment, 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.

The following are some precautionary suggestions:

- 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.
- If it is a flu season, get a flu shot.
NERVE AND MUSCLE PROBLEMS
Certain chemotherapy drugs can cause peripheral neuropathy, a nerve problem that causes you to experience tingling, burning sensations, pins and needles, loss of balance, and numbness in your hands and feet. It can make it difficult to pick things up and to use your hands for things like buttoning your shirt. If you experience these symptoms, talk to your doctor. He or she may be able to suggest ways to manage the neuropathy. It may also be necessary to alter your chemotherapy drug dosage, or change your treatment.

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 (NSAIDs), can be used to treat mild discomfort. Your healthcare provider may prescribe other classes of medication, such as anti-depressants (often in smaller doses than are used to treat depression) and anti-convulsants, to help specifically with nerve pain.

The following are some things you can do if you are suffering from a neuropathy:

• Take your pain medications. Most work best if they are taken before the pain gets bad.

• Don’t drink alcohol. It may make the neuropathy worse.

• Allow yourself extra time to do things.

• If the neuropathy is in your feet, sit down as much as possible, even while brushing your teeth.

• Talk with your doctor or healthcare team about the problems you are having. They might be able to come up with ways to help you feel better.

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

• Be careful when bathing. Use non-skid bathmats and use warm (not hot) water; consider using a shower chair and hand rails

• Use potholders to prevent burns when cooking

• Be careful when you use a knife, scissors, or any other sharp objects

• 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 an increased sensitivity 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 rating of 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 chafing.
• Stay clean and dry: Use mild soap when bathing; rinse and pat dry. Avoid using hot water when bathing to prevent skin irritation.

NUTRITION
One of the most important things you can do for yourself as you undergo treatment for recurrent ovarian cancer is to eat healthily. But treatment may make you lose your appetite. 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 easily follow. It is recommended that this plan consists of 5 fruits and vegetables a day. (Note: Fresh fruits and vegetables should be avoided if you are neutropenic.) It is also suggested that you eat chicken and fish, and avoid red meat.

• Maintain a well-balanced diet: If you feel nauseated, eat plain carbohydrate foods, such as toast, pretzels, crackers, oatmeal, noodles or white rice.
• Eat smaller, more frequent meals: Eat smaller portions, more often, throughout the day. If you have decreased appetite, keep favorite foods on hand to help you eat more.
• 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. If you often feel tired, buy foods that need little or no work to prepare.
• Make eating enjoyable: Dine with family or friends, play music, or set a tranquil mood with candles.

EXERCISE
While it may 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 your 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.

COMPLEMENTARY AND INTEGRATIVE TREATMENTS
Some women with ovarian cancer turn toward the whole-body approach that complementary and alternative medicine (CAM) provide to enhance their fight against the disease, as well as to relieve stress and minimize side effects. CAM therapies are a diverse range of practices and products that are used in conjunction with traditional medicine.

Many women have tried, and benefited from, the following CAM therapies. You might want to speak with other women with cancer or your healthcare team, to see which therapies they feel are most helpful, or might work best, for you and your lifestyle. Also, talk with your healthcare team before you try any of these to make sure they won’t interfere with your cancer treatment.

• Acupuncture is a centuries-old Chinese technique that involves the insertion of small needles just below the surface of the skin. It is used to relieve acute and chronic pain, help treat nausea, and alleviate hot flashes and other side effects of cancer drugs.
• Aromatherapy is the use of essential oils from flowers, herbs, and trees to promote health and well-being.
• Biofeedback is a method that uses a special machine to help you learn how to control certain body functions, such as heart rate, skin temperature, or blood pressure.
• Dietary supplements include vitamins, minerals, herbs, and botanicals that are sold as natural alternatives to pharmaceuticals. Check with your doctor before starting new supplements, as they may interact or interfere with your treatment.
• Imagery is imagining details of a safe, comfortable place, or a positive experience, to feel more relaxed, which can lower blood pressure and help promote healing.
• Massage therapy involves manipulating the body’s muscles and soft tissue through gentle rubbing, kneading, and patting. There are many different types of massage to ease pain and support healing.
• Meditation is focused, conscious breathing, or repetition of certain words, to relax the mind and body.
• Qi Gong (chee-GUNG) is 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 and Tai Chi involve postures, movements, and breathing exercises to strengthen and heal the body, mind, and spirit.

COMPLEMENTARY AND ALTERNATIVE MEDICINE DIFFERENCES

Many people are confused about the differences between complementary and alternative medicine, often referred to by the acronym CAM. “Complementary medicine” refers to the use of CAM together with conventional medicine, such as using ginger syrup to prevent nausea during chemotherapy. “Alternative medicine” refers to the use of CAM in place of conventional medicine. Many medical experts prefer to use the more contemporary term “integrative medicine” (also called integrated medicine). According to the National Center for Complementary Medicine, integrative medicine refers to a practice that “combines both conventional and CAM treatments for which there is evidence of safety and effectiveness.”
MANAGING YOUR EMOTIONS

• Recognizing When You Are Stressed Out
• Managing Anxiety
• What About Support Groups?
• Managing Depression and Sadness
• Making the Most of Sexuality and Intimacy
• End of Life Concerns
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 backache, dizziness, pain, heartburn, dry mouth, difficulty concentrating and making decisions, increased or decreased appetite, frequent crying spells, frustration, and irritability.

RECOGNIZING WHEN YOU ARE STRESSED
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.
- Lack of concentration, making it difficult to perform usual daily tasks.

MANAGING ANXIETY
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.

Some signs of anxiety:

- Feeling uneasy and tense
- Feeling of restlessness, uncertainty, and dread
- Sweating a lot
- Having a rapid heart rate or feeling your heart pounding in your chest
- Having a knot in your stomach

In addition, some people experience shakiness or have difficulty falling asleep. Sometimes individuals become overly fearful and no longer cope well with day-to-day life.
STRESS-REDUCING ACTIVITIES

• Breathing exercises or meditation
• Getting a massage
• Listening to relaxation CDs
• Taking a drive or spending time in nature
• Watching a funny movie or TV show
• Playing with your dog or cat
• Taking a class
• Knitting, crocheting, or needlepoint
• Exercising or gentle stretching
• Taking up a new hobby

WAYS TO COPE
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.
• 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.
• Consider asking your doctor for a counseling referral.

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, or being dizzy).
• Ask your family members and friends how your anxiety is affecting them.

MEREDITH, ARIZONA

“The journey has many twists and turns. Surround yourself with people that help you rise. Don’t let cancer define you and be kind to your soul. Raise your voice. Advocate for yourself and future generations. Most importantly - know you are not alone.”
WHAT ABOUT SUPPORT GROUPS?
You may have heard about support groups, or peer to peer programs, available in your area for women with recurrent ovarian cancer. In a support group, you can talk about your feelings and what you are going through. Support groups can meet in person, on the phone, or over the Internet. There are also blogs for women with ovarian cancer that can be a source of information and support.

If you think you might be interested in a support group, ask the healthcare team at your cancer care center, hospital, or oncology group if they offer one. Or, call a nearby cancer center or university hospital and ask if there is a support group in your community.

Some people prefer phone support groups or want to try one on the Internet. Online support groups are especially good if you are experiencing side effects from therapy or have difficulty leaving your home. They also allow you to be more anonymous, which may enable you to be more candid about your feelings and fears.

If you think you might be interested in a support group, here are some options:

**National Ovarian Cancer Coalition** — Contact the NOCC to learn if there is a local chapter in your community, which can provide you with resources and tremendous support, by visiting www.ovarian.org.

**American Cancer Society** — The American Cancer Society offers the Cancer Survivors Network and information on local support programs. Call 1-800-ACS-2345 to speak to an information specialist.

**CancerCare** — A national nonprofit that offers free online and telephone support groups for anyone affected by cancer. Cancer Care also offers face-to-face support groups for those living in the New York Tri-State area. All the support groups are led by professional oncology social workers. To learn more, call 1-800-813-4673 or visit www.cancercare.org.

**CancerConnect** — An online, HIPAA compliant platform for those affected by ovarian cancer to gain support and share information.

**Cancer Support Community (formerly The Wellness Community and Gilda’s Club)** — This nonprofit offers a variety of free online support groups for people with cancer and their loved ones. Call 1-888-793-9355 or go to www.cancersupportcommunity.org.

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**SANDRA, FLORIDA**

“Originally diagnosed with Stage IIIC ovarian cancer in 2006 I was told I would live three to four years. When cancer returned four years later my thought was “well they must have been right”. Seven years after my recurrence I am not only here, but thriving. Ovarian cancer doesn’t define me, it’s a part of my life, but I refuse to let it control me. Never give up, fight the good fight, you never know what lies ahead.”
MANAGING DEPRESSION AND SADNESS

Understandably, you may feel sad if you have to deal with recurrent ovarian cancer. 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

Many women describe depression as the darkest time of their life. Many report crying for long periods of time or many times each day, as well as problems with sleep (either sleeping all day or not getting 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.

THE CAUSES OF DEPRESSION AND SADNESS

Depression can occur as a result of specific events, such as the diagnosis of 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. But if it lasts more than two weeks, talk to your doctor for possible counseling or medication.

Family members and friends can help. You can 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 that you find stressful, such as going to your doctor visits or helping with household chores.
- Notify your doctor or nurse for you, when needed.

If you feel that you want to hurt or kill yourself or others, call your doctor immediately, or call a national suicide hotline at:

1-800-SUICIDE (1-800-784-2433)  
1-800-273-TALK (1-800-273-8255)

Or, call 911 and ask for help.

Tell them you are in suicidal danger.
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 gardens or parks.

• 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 (for example, walking for 20 minutes, 3-5 times per week). 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.

• Make an appointment with a counselor, spiritual advisor, or psychologist.

• If medicines have been ordered for your depression, take them as directed.
END OF LIFE CONCERNS
Women are living longer, thanks to new treatments, and your medical team will work with you to plan a sequence of treatments to fight your cancer. However, a recurrence of ovarian cancer usually generates concerns about the end of life.

Although talking with your loved ones about the specific medical care you might want is upsetting, it can protect your family from having to make decisions about what you want done if you are unable to speak for yourself. Usually, once the subject is discussed, everyone feels a sense of relief.

MAKING YOUR WISHES KNOWN
Advanced Health Directives
An advanced health directive is a signed, written document that lets your family and doctors know what choices you would want them to make if you are too ill to communicate or are unconscious. It is your voice when you can’t speak for yourself. The two major types of directives are a living will and a durable power of attorney for healthcare.

1) Living Will
A living will is a document that explains your wishes for medical care when you cannot make your own decisions. Before your living will can guide medical decision-making, two physicians must certify that you are unable to make medical decisions and you are in a condition described in your state’s living will law (such as “permanent unconsciousness”). 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) Durable Power of Attorney for Healthcare
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. The person you appoint is called your agent. Depending on 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. Your agent does not have to be an attorney; most people choose a close family member or friend. 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.

You can get a copy of an advance directive form from a hospital, an attorney, a library, or an organization that advocates for people facing end of life concerns. You can also get information from Last Acts Partnership, a non-profit organization that provides information on state-specific advance directives and forms. Last Acts Partnership can be contacted at 1-800-989-9455 or www.lastactspartnership.org.
Do Not Resuscitate

A Do Not Resuscitate or DNR 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 stops beating. Once this decision is made, your doctor places a DNR order in your chart. This order, which may also include considerations related to medicines to increase blood pressure or prevent arrhythmia, or ICU transfer, depending on the facility, are renewed upon subsequent hospitalizations.

Other similar considerations include administering medications to increase blood pressure or prevent arrhythmias, as well as ICU transfer.

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 your family. It ensures that your wishes are respected.

Hospice

If you decide that you no longer wish to receive chemotherapy or other therapies to treat the cancer, the focus will shift 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. This 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. Hospices employ experts in medical, 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 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.

For more information about talking with family and friends, please access NOCC’s brochure entitled “When a Loved One Has Ovarian Cancer,” which is available at WWW.OVARIAN.ORG
GLOSSARY OF CANCER TERMS
The following glossary includes many terms you will be hearing regularly and may be helpful to you throughout your cancer treatment.

Alopecia: Partial or complete loss of hair resulting from chemotherapy or radiation.

Anemia: A condition in which the body does not have enough red blood cells. This may be due to bleeding or lack of blood production by the bone marrow. Symptoms include tiredness, shortness of breath, and weakness.

Antiemetics: Drugs given to minimize or prevent nausea and vomiting.

Ascites: An accumulation of fluid within the abdomen that can occur in women with noncancerous conditions and with different types of cancers.

Benign: Non-cancerous.

Biopsy: A surgery performed to remove tissue for examination in order to determine whether cancer is present.

CA-125: A blood protein that can be measured and is an important tumor marker in ovarian cancer.

CBC (Complete Blood Count): A series of tests including red and white blood cell platelet counts as well as hemoglobin and cell volume measurement.

Cancer: Any of a group of diseases whose symptoms are due to the unrestrained growth of cells in one or more of the body’s organs or tissues.

Carcinogens: Substances known to cause and/or promote cancer.

Carcinoma: Cancer that begins in the internal tissues.

Catheter: A flexible tube through which fluids enter or leave the body.

Chemo Brain: Cognitive impairment during and sometimes after chemotherapy.

Chemotherapy: The treatment of cancer by chemicals (drugs) designed to destroy cancer cells or stop them from growing.
Clinical Trial: A type of research study that tests how well new drugs or treatments work in people. Also called a clinical study or research study.

CT or CAT Scan (Computerized Axial Tomography): A diagnostic procedure that combines an X-ray with a computer to produce highly-detailed cross-sectional, three-dimensional pictures of the entire body. These tests are generally 100 times more detailed than X-rays.

Cyst: A fluid-filled sac.

Diagnosis: The act of identifying a disease from its signs and symptoms.

Edema: Swelling due to the accumulation of fluid within the tissues.

Epithelial: Type of tissue lining the skin and hollow organs.

Estrogen: Female sex hormone secreted primarily by the ovaries that is responsible for secondary sex characteristics such as the growth of breasts.

Estrogen Receptor Test: A test done during the biopsy of cancerous tissue to determine if its growth depends on estrogen.

Gynecologic oncologist: A doctor who specializes in treating cancers of the female reproductive organs.

HE-4 Test: Blood test to monitor the recurrence or progression of ovarian cancer.

Hematologist: A physician (internist) who specializes in blood diseases.

Hormones: Naturally occurring substances that are released by the endocrine organs and circulated in the blood. Hormones control growth, metabolism, reproduction, and other functions.

Hysterectomy: Surgical removal of the uterus and, sometimes, the cervix. Removal of the entire uterus and the cervix is referred to as a total hysterectomy.

Infusion: Slow intravenous delivery of a drug or fluids.

Intraperitoneal: Administration of drugs directly within the peritoneal cavity. Also called IP.

Intravenous: Administration of drugs or fluids directly into a vein.

Invade: To invade refers to the ability of cancer cells to enter and permeate new sites in the body. A malignant ovarian tumor can grow and invade organs next to the ovaries, such as the fallopian tubes.

Malignant: A term used to describe a cancerous tumor.

Menopause: Point at which menstruation ceases, marking the end of a woman’s reproductive years.

Metastasis: The spread of cancer to one or more sites elsewhere in the body.
MRI (Magnetic Resonance Imaging): A sophisticated technique to examine the body using powerful electromagnets, radiofrequency waves, and a computer to produce internal pictures of the body.

Neutropenia: An abnormal decrease in the number of neutrophils, a type of white blood cell.

Omentum: A fold of fatty internal abdominal tissue where ovarian cancer often spreads.

Oncologist: A physician who specializes in cancer therapy and handles general medical problems that arise during the disease.

Oophorectomy: Surgery to remove one or both ovaries.

Outpatient: A patient who has diagnosis or treatment at a healthcare facility without spending the night.

Pelvis: The lower part of the abdomen, located between the hip bones.

Peripheral Neuropathy: A possible side effect of chemotherapy that affects the nervous system. Symptoms include tingling, burning, weakness, or numbness of the hands or feet.

PET Scan: A diagnostic procedure in which a small amount of radioactive sugar is injected into a vein and the body is scanned.

Port: An implanted device through which drugs can be infused without repeated needle sticks.

Prognosis: A statement about the likely outcome of disease in a particular patient.
The following resources offer credible programs and information that will be helpful to you as you seek information and answers. Keep in mind—especially as you seek information on the Internet—not all sites offer scientifically validated or accurate information and some fringe sites can be needlessly alarming. Narrowing your search to well-known organizations and government sources will help ensure the credibility of information. For more resources, go to the NOCC’s website, ovarian.org.

**Women’s Cancer-Specific Organizations**

**National Ovarian Cancer Coalition**  
**888-OVARIAN (888-682-7426)**  
ovarian.org  
The NOCC is the leading ovarian cancer public information and education organization in the U.S. Help and hope for ovarian cancer patients and their families is provided through a nationwide network of chapters, a toll free information line, a comprehensive website, peer support, informational literature, and special awareness projects.

**FORCE: Facing Our Risk of Cancer Empowered**  
**866-288-RISK (866-288-7475)**  
facingourrisk.org  
FORCE is a nonprofit organization for women who are at high risk of developing breast and ovarian cancers due to their family history and genetic status, and for members of families in which a BRCA mutation may be present.

**Foundation for Women’s Cancer**  
**312-578-1439**  
foundationforwomenscancer.org  
The Foundation provides programs to benefit women who have, or who are at risk of developing a gynecologic cancer. These programs raise awareness of ways to prevent, detect, and treat gynecologic cancers while providing education and support.

**Ovarian Cancer Research Fund Alliance**  
**866-399-6262**  
ocrfa.org  
OCRFA is devoted to the formation of early diagnostic treatment programs and research toward ending ovarian cancer.
General Cancer Information

American Cancer Society
800-ACS-2345 (800-227-2345) cancer.org
The American Cancer Society is dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives and diminishing suffering from cancer through research, education, advocacy, and service.

Cancer.Net
888-651-3038 cancer.net
Links all American Society of Clinical Oncology information and materials to help patients and families make informed health-care decisions.

National Cancer Institute
800-4-CANCER (800-422-6237) cancer.gov
An arm of the U.S. National Institutes of Health (NIH), the NCI provides comprehensive information about cancer, cancer clinical trials, and the latest research developments.

National Center for Complementary and Alternative Medicine
888-644-6226 nccam.nih.gov
The nation’s lead agency for scientific research into the diverse medical and health care systems, practices, and products that are not generally considered part of conventional medicine.

National Coalition for Cancer Survivorship
877-NCCS-YES (877-622-7937) canceradvocacy.org
The oldest survivor-led advocacy group in the country. Provides information on cancer support, advocacy, and quality-of-life issues.

Patient/Caregiver Support Organizations

Bright Pink
bebrightpink.org
Bright Pink is a national organization that provides education and support to young women who are at high risk for ovarian and breast cancer.

CancerCare, Inc.
800-813-HOPE (800-813-4673) cancercare.org
CancerCare is a national nonprofit organization that provides free professional support services to anyone affected by cancer: survivors, caregivers, children, loved ones, and the bereaved.

Cancer Hope Network
877-HOPENET
cancerhopenetwork.org
Provides free and confidential one-on-one support to cancer patients and their families. Cancer patients or family members are matched with trained volunteers who have undergone and recovered from a similar cancer experience.

Cancer Support Community
877-793-9355 cancercsupportcommunity.org
In 2009, Gilda’s Club Worldwide and The Wellness Community joined forces to become the Cancer Support Community. CSC provides support and networking groups, counseling, education and healthy lifestyle programs through a network of more than 50 local affiliates and 100 satellite locations. Listings of local Gilda’s Clubs can be found through the CSC website.

Caring Bridge
651-452-7940 caringbridge.org
Provides free websites that connect people experiencing a significant health challenge to family and friends.
LIVESTRONG
855-220-7777
livestrong.org
Helps those with cancer and their loved ones live strong through education, advocacy, public health events, and research.

Look Good...Feel Better
800-395-LOOK (800-395-5665)
lookgoodfeelbetter.org
Look Good...Feel Better is a free, non-medical, brand-neutral, national public service program to help women offset appearance-related changes from cancer treatment.

Lotsa Helping Hands
lotsahelpinghands.com
This free website helps families, friends, colleagues and neighbors to create a private community to keep track of appointments, meals, rides, daily tasks, and who has volunteered to do what.

MyLifeLine
mylifeline.org
Provides free, personal websites for cancer patients to connect with their friends and family during the treatment process.

Patient Advocate Foundation
800-532-5274
patientadvocate.org
This organization serves as an active liaison between the patient and their insurer, employer and/or creditors to resolve insurance, job retention, and/or debt crisis matters related to their diagnosis. The staff includes case managers, doctors, and attorneys.

Planet Cancer
planetcancer.org
This is an online community for young adults with cancer.

SHARE
844-ASK-SHARE
sharecancersupport.org
SHARE’s mission is to create and connect a community of women affected by ovarian or breast cancer with support groups, events, educational programs, and advocacy activities.

Travel & Housing Organizations
Air Charity Network
877-621-7177
aircharitynetwork.org
A network of seven organizations that provide free flights for patients who need to travel for medical treatment.

American Cancer Society
Hope Lodge Program
800-ACS-2345 (800-227-2345)
cancer.org
The ACS Hope Lodges offer free housing to patients and their caregivers when having to travel out of town for treatment.

Joe’s House
877-563-7468
joeshouse.org
Joe’s House provides a nationwide online service to help patients and their families find lodging near treatment centers.

National Association of Hospital Hospitality Houses, Inc.
800-542-9730
hhnetwork.org
Offers accommodations to families and their loved ones receiving medical treatment away from home.
We know that it is difficult to have to go through treatment for cancer again. We hope that the knowledge and understanding you may have gained by reading this guide gives you the strength to face recurrent ovarian cancer.

This guide provides a lot of information and we hope it is a helpful reference. But remember, this guide 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 the NOCC to be connected with a local chapter.

As always, if you have any questions, feel free to contact us at 1-888-OVARIAN (682-7426) or visit our website, www.ovarian.org. If, for any reason, we are unable to answer your question, we will direct you to someone who can.

In the spirit of care and support, we encourage you to be kind to yourself, and treasure every day by living life to the fullest.

With support and encouragement,
National Ovarian Cancer Coalition
“You gain strength, courage and confidence by every experience in which you really stop to look fear in the face. You are able to say to yourself, ‘I have lived through this horror. I can take the next thing that comes along.’ You must do the thing you think you cannot do.”

ELEANOR ROOSEVELT

“Some days there won’t be a song in your heart. Sing anyway.”

EMORY AUSTIN

“I can be changed by what happens to me. But I refuse to be reduced by it.”

MAYA ANGELOU

“You beat cancer by HOW you live, WHY you live, and the manner in which you live.”

STUART SCOTT

“Don’t count the days; make the days count.”

MUHAMMAD ALI
“What lies behind us and what lies before us are tiny matters compared to what lies within us.”

RALPH WALDO EMERSON

“My mission in life is to not only survive, but to thrive; and to do so with some passion, compassion, some humor, and some style.”

MAYA ANGELOU

“Believe in yourself and all that you are. Know that there is something inside you that is greater than any obstacle.”

CHRISTIAN D. LARSON

“See every difficulty as a challenge, a stepping stone, and never be defeated by anything or anyone.”

EILEEN CADDY

“Courage does not always roar. Sometimes courage is the quiet voice at the end of the day saying, ‘I will try again tomorrow.”

MARY ANNE RADMACHER
“See every difficulty as a challenge, a stepping stone, and never be defeated by anything or anyone.”

— EILEEN CADDY
OUR ANTHEM

There is a ribbon that runs through everything we do. But it’s not just a teal symbol for people to wear on their lapels. It is a ribbon forged from hope. From grief. From love. It is a ribbon we use to wrap around those needing comfort as they rebuild. It is a ribbon we use to tie us all together. And it is a ribbon we wave to educate and encourage every woman to be aware. Our enemy is ruthless. And that is why for more than 25 years, the National Ovarian Cancer Coalition has provided a ribbon of courage for women and their families facing the ovarian cancer battle. Together we are strong and we will never back down.