Ovarian Cancer
Quality of Life Issues

NOCC
National Ovarian Cancer Coalition
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Quality of life issues are an extremely important part of treatment and post-treatment screening in women with ovarian cancer. While these women are fighting for their lives, they are also concerned about being bald, feeling sexy, and overcoming fatigue. Women want to know the effects of therapy on quality of life (QOL), and deserve to have this information.

This booklet provides timely and practical information about quality of life concerns.

We hope it will be a valuable resource to women with ovarian cancer, their loved ones, and the healthcare team.

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Treatment for ovarian cancer usually involves surgery followed by chemotherapy. You may experience physical, emotional, and/or psychological side effects related to your cancer and the treatment of your specific disease. The key to proactively managing side effects begins with good communication with the healthcare team. Although your doctor or nurse may not ask you about specific side effects, it is extremely important for you to bring them to the attention of your healthcare team. Often patients underreport side effects because they do not want to be viewed as weak or as complaining. Some side effects may be easily controlled or even stopped; others may be more serious in nature and require additional supportive care. Your job is to report the side effects. Your healthcare team will then work with you to help treat and hopefully resolve them.

The best way to communicate to your healthcare team is by providing specific information about bothersome side effects. Keeping a diary is a good way to make sure that information about side effects you experience are written down in one place.

The content of the diary may include answers to questions that the healthcare team will want to know:

- What type of side effect are you experiencing?
- When does it occur?
- How does it occur?
- How severe is it when it happens?
- How bothersome is it in your day-to-day life?
- Does anything make it better or worse?
- How have you tried to manage the problem?

**Side Effects from Surgery**
Surgery is the cornerstone of most treatment for ovarian cancer. It is important to recognize that some surgical side effects can significantly impact your emotional and physical quality of life.

**Loss of Fertility**
In addition to dealing with a new diagnosis of cancer, loss of fertility due to surgery for ovarian cancer can be one of the most difficult issues that women face. Women who have not completed childbearing or who have not yet begun to start their families may experience the loss of fertility in different ways. It is important for these women to have strong support systems such as family members, and counselors. Additionally, support groups such as Resolve: The National Infertility Association (www.resolve.org) and Fertile Hope, a non-profit advocacy group that tries to improve healthcare and insurance coverage for cancer-related infertility (www.fertilehope.org), offer resources to help women and their partners.
Surgical Menopause
Surgery for ovarian cancer may result in what is called a "surgical menopause." Unlike natural menopause in which menopausal symptoms may occur gradually over time, women experiencing surgical menopause may find that these symptoms are more immediate and profound.

In addition to menopausal symptoms, women need to be aware of the increased risk of heart disease and osteoporosis resulting from the loss of estrogen. Because the decision to use hormone replacement therapy needs to be made based upon a woman’s individual symptoms and health concerns, you should check with your doctor to see whether hormone replacement therapy is right for you.

Other things that you can do to minimize your risk of heart disease and osteoporosis include doing weight-bearing exercise on a regular basis, eating a healthy and balanced diet, and taking calcium supplements. More information is available from "Frequently Asked Questions about Hormone Therapy" published on the American College of Obstetricians and Gynecologists’ website www.acog.org.

Sexual Concerns
If you have experienced loss of desire for sex, you are not alone. This is one of the most common sexual problems of women with ovarian cancer. For more on this topic please refer to the Sexuality/Intimacy/Relationship portion of this booklet. Another excellent resource is the booklet “Ovarian Cancer: Sexuality and Intimacy,” available from the National Ovarian Cancer Coalition (1-888-OVARIAN, www.ovarian.org).

Bowel Obstruction
Bowel obstruction due to surgery happens when scar tissue grows into the intestine causing the intestine to become blocked. This can result in severe constipation, abdominal cramping, nausea and vomiting. These symptoms need to be reported to your doctor immediately; he/she will determine whether simple dietary changes might help relieve the obstruction or whether more aggressive medical or surgical interventions may be necessary.

A bowel obstruction can also occur due to involvement of the bowel with tumor. In addition to nausea and vomiting, patients can also experience severe pain and/or constipation. Report these symptoms to your doctor immediately. Sometimes a low residue/low fiber diet can help. In other cases, surgery may need to be performed. The decision for surgery will depend on a variety of factors including how you feel, what your imaging studies look like, the status of your cancer, and how you respond to less aggressive interventions.

Ostomy
Undergoing surgery for an ostomy can be a difficult experience. Whether this change in your life is temporary or permanent, it still takes some getting used to. Most hospitals have ostomy nurses to help patients learn about care and management of their ostomy. Check with your enterostomal (ET) nurse to see if he or she knows a patient with an ostomy who might be willing to talk with you. Talking with someone in the same situation can often help address your concerns. Another resource is the United Ostomy Association (1-800-826-0826 or www.uoa.org).
Chemotherapy Side Effects
When people consider the side effects of cancer treatment, most probably think about chemotherapy-related side effects. Chemotherapy is medication that is designed to attack the fast-dividing cancer cells. While this is good for attacking the cancer cells, chemotherapy medications can also attack healthy cells in your body, resulting in adverse side effects.

If you are scheduled to undergo chemotherapy, be sure to ask your doctor and/or nurse about what types of side effects your chemotherapy may have. Be aware that there are many kinds of chemotherapy – and each has its own particular side effect profile.

The side effects listed in this section include only some of the most commonly-occurring ones associated with chemotherapy used to treat ovarian cancer.

Gastrointestinal Side Effects
The gastrointestinal (GI) tract encompasses the mouth, throat, stomach and small and large intestine.

Chemotherapies that affect the GI tract may result in problems with nausea, vomiting, and loss of appetite. Nausea and vomiting have been found to be two of the most bothersome side effects caused by chemotherapy. Fortunately, over the past couple of decades, many advances have been made in medications used to treat these side effects (these medications are called antiemetics).

While some chemotherapy can cause nausea and vomiting within the first 12-24 hours, other chemotherapy regimens may cause delayed nausea several days after chemotherapy is administered. Although most women routinely receive antiemetics during chemotherapy, you should check with your doctor or nurse just to make sure you are. You should also make certain you take the medication at the right time; antiemetics are given prior to chemotherapy and some may need to be taken up to a few days after treatment.
It is particularly important to let your doctor know if the specific antiemetic medication prescribed for you does not work, as several kinds of antiemetics are available and may work better for you. Some of the medications your doctor may prescribe to treat nausea and vomiting include Decadron®, Compazine®, Ativan®, Kytril®, Zofran®, Aloxi® and Emend®. Finally, make sure you drink plenty of water before each chemotherapy treatment as this can also help minimize your risk of nausea and vomiting.

Chemotherapy may interrupt your normal bowel function, resulting in either constipation and/or diarrhea. Although some women are embarrassed to discuss these side effects with their doctor, it is important to let your healthcare team know since both can result in major problems if not treated. As with any side effect, it is advised that you note when you experience it (e.g. the day of chemotherapy, the day after, etc.). This may help your doctor determine what can be done to minimize or eliminate the side effects.

For women experiencing constipation, experts recommend a diet high in fiber with generous fluid intake (water, fruit juices) along with regular exercise such as walking. If these tips are not helpful, constipation may be relieved by taking laxatives such as Senokot® or Colace®. Use caution when taking laxatives since overuse may result in diarrhea. For women experiencing diarrhea, check with your doctor to see if you should reduce your dietary fiber intake and whether you should take anti-diarrhea medications. Make sure you replace your fluids since severe diarrhea can result in dehydration. Use caution when taking medications since overuse may result in constipation.

**Taste Bud Changes and Loss of Appetite**

Some women find that their sense of taste changes as a result of chemotherapy. Common changes include a sour or metallic taste in the mouth. To help manage this side effect consider sucking on mints or hard candy, and using plastic utensils instead of metal.

If you are experiencing loss of appetite, try avoiding processed foods, drink plenty of water, and try nutritional supplement beverages.

Let your healthcare team know about appetite changes and subsequent weight loss or weight gain. Most hospitals have registered dieticians and nutritionists on staff, so consider setting up an appointment to work out a good diet plan.

Several helpful publications are available as well. *Betty Crocker’s Living with Cancer Cookbook: Easy Recipes and Tips Through Treatment and Beyond* (2002) was written by two gynecologic oncologists and a nutritionist. The National Cancer Institute (www.cancer.gov) and the American Cancer Society (www.cancer.org) also provide information about eating and nutrition for cancer patients.

**Peripheral Neuropathy**

Peripheral neuropathy occurs when a group of nerves is either damaged or injured. Symptoms of this side effect may involve pain and numbness or heaviness in the hands/fingers and feet/toes. Some women have described the feeling as “pins and needles.”
If you experience this side effect, you may notice that you have increased difficulty doing certain tasks such as picking up or holding small objects, sewing, writing, buttoning clothes or going up or down stairs. Some women have reported ringing in the ears or difficulty hearing (ototoxic side effects), while others have noticed blurred or double vision.

Let your doctor or nurse know about any symptoms you experience since the severity and intensity of peripheral neuropathy varies with each woman. In particular, tell your healthcare provider if you experience burning or pain, and if you have difficulty with daily activities.

For some women, peripheral neuropathy becomes more severe over time (and may increase as more cycles of chemotherapy are given); in other women, the symptoms gradually decrease or disappear altogether 6-12 months after chemotherapy is completed. While doctors have not yet found a way to prevent peripheral neuropathy, there are some things that may be done to decrease the symptoms.

**Talk to your doctor to learn more about the following:**
- Glutamine®
- Antihistamines
- Warmth and massage
- Anticonvulsants
- Walking
- Arthritis medications
- Amifostine®
- Topical patches or creams - such as capsaicin or lidocaine
- B vitamins
- Acupuncture
- Antidepressants

If you are experiencing difficulty walking or with balance, suggestions to make your living arrangements safer during this time include:
- Provide adequate lighting in your house
- Leave lights on at night
- Cover steps/stairs and hard floors with non-skid materials
- Minimize clutter in hallways and stairways
- Tape down edges of area rugs
- Put a non-skid bathtub mat inside your bathtub
- Avoid wearing shoes that make walking difficult
- Check your hands and feet daily to look for open sores/irritation

**Chemo-Brain**
Chemo-brain refers to what some women describe as forgetfulness, “slowed” thinking, difficulty thinking of words and names, and difficulty writing. Some women experience chemo-brain during chemotherapy; others find that it may continue even after chemotherapy. Most women indicate that this side effect is temporary and that it eventually goes away. Experts do not fully understand why chemo-brain occurs, but it may be helpful to keep a diary to note if, when and how you experience this side effect.
Alopecia
Many chemotherapies affect the cells that make hair follicles. As a result, you may notice that you begin to experience hair loss approximately 3 weeks after you receive the first cycle of certain chemotherapies such as paclitaxel. You may find that your scalp tingles or itches, and that your hair falls out in large amounts. In addition to hair on your head, alopecia may result in loss of all body hair (eyelashes/brows, pubic hair, arms/legs).

Although your hair usually starts to grow back several months after you finish chemotherapy, it sometimes starts growing back after 5 or 6 cycles. This does not mean that the chemo is not working. Some women find that their “new” hair is a different texture and color.

Unfortunately, hair loss is one of the most visible signs of cancer treatment and no therapy exists to prevent this from occurring. Some women will cut their hair shorter or shave their hair off in advance. You may decide to wear a wig, scarf or cap during chemotherapy. Or, you may decide that you feel more comfortable wearing nothing on your head. The American Cancer Society and National Cancer Institute offer excellent patient materials to help women manage hair loss during cancer treatment.

Myelosuppression
This term refers to the decrease in blood cell production by the bone marrow. Chemotherapies can cause temporary decreases in white and red blood cells and platelet counts. Chemotherapy given to many women with ovarian cancer causes myelosuppressive side effects. These are usually temporary and can be managed effectively. Counts go down after chemotherapy is given and tend to normalize by the time your next chemotherapy cycle is scheduled. If counts do not recover in time for your chemotherapy appointment, your doctor may delay your treatment until the counts return to normal. Different types of myelosuppressive side effects can occur; each can have potentially serious health consequences so make sure you understand when it is necessary to contact your healthcare team.

Neutropenia refers to a significant decrease in white blood cell count. Since white blood cells help your body fight infection, being neutropenic can make you more prone to infection. If you are neutropenic, it is a good idea to avoid close contact with people who have been sick with a cold or the flu as well as crowded areas such as airplanes.

If you experience fever, you should immediately contact your doctor. If your white cell count drops to extremely low levels, your doctor may put you on antibiotics to help fight infections as well as give you injections of medications such as Neupogen® or Neulasta® that stimulate your white cell production.

Anemia refers to a significant decrease in red blood cell counts. Since red blood cells transport oxygen to healthy tissues in your body, women who are anemic may feel short of breath after light activity and can tire easily. If you are anemic, you should take time to rest and recover for several days following chemotherapy. Talk to your doctor.
about including a diet of iron-rich foods or taking an iron supplement. If you find that fatigue is preventing you from doing many of your normal activities, ask your doctor about Procrit® or Aranesp®, medications to help your bone marrow produce more blood cells. Some doctors may recommend blood transfusions to help boost red blood cell counts, as it takes several weeks to see results from Procrit® or Aranesp®.

**Thrombocytopenia** refers to a decreased level of platelets. Platelets help the body when bleeding occurs via clotting. If you are thrombocytopenic, avoid cuts and scrapes/bruises. Your doctor will advise you to avoid medications containing aspirin. If your platelet count drops to dangerously low levels, your doctor may recommend platelet transfusions to help your body restore its platelet levels.

**Fatigue**

Fatigue is an extremely common problem for cancer patients and survivors. Research has shown that 72% to 99% of all cancer patients report problems with fatigue. People with cancer experience fatigue much differently than do healthy individuals. People with cancer describe fatigue as a chronic, unpleasant, distressing, life-and-activity limiting tiredness throughout the day that is not relieved by sleep and rest, while healthy people view fatigue as a normal, even pleasant part of daily life.

The causes of cancer-related fatigue are not well understood. In all likelihood, it is caused by multiple factors. Sometimes cancer treatment can cause anemia or other toxicities that can lead to fatigue, but not all fatigue is explained by easily identifiable medical reasons.

One theory is that the decrease in physical activity that occurs when someone is diagnosed with cancer leads to a physical deconditioning. Because you’re not using them as much, your muscles, heart, and lungs become weaker and make it more difficult for you to do the same amount of work that you could do easily before cancer. This is probably why moderate exercise decreases fatigue for some people.

If you are experiencing fatigue that interferes with your usual activities and is distressing to you, discuss this with your doctor. He or she can evaluate whether some treatable condition, like anemia, thyroid issues, poor pain control, sleep problems, or depression might be causing the fatigue. If any of these conditions are present you may find that treating them improves your fatigue as well.

Once you have done all of the above and still find you have no energy, there are a number of other things you can do to cope with or decrease your fatigue. One strategy is called energy conservation.

The following energy conservation tips may be helpful to you:

- Identify ways that necessary activities can be done using less energy (e.g., sitting while showering or preparing food)
- Schedule tasks that take the most energy at times of the day when you have the most energy
- Set priorities, eliminate non-essential activities, and delegate tasks to others when possible
Some women find that stress management strategies described in the Depression, Anxiety and Distress section are helpful in coping with fatigue. Several studies have shown that exercise is helpful in reducing fatigue. Most of these studies have been conducted among breast cancer patients and survivors, but evidence shows the benefits of exercise for people with other types of cancer as well.

Before starting any exercise, talk to your doctor to make sure the type of exercise you want to do is right for you.

For example, if you have bone metastases or severe peripheral neuropathy, your doctor may advise you to avoid weight-bearing exercise like walking. If you experience a lot of fatigue, moderate intensity exercise, such as brisk walking, is probably better than very intense activity. If you are exercising at a moderate pace, you will notice your heart beating faster and your breathing rate increasing, but not so much that you are unable to talk. One guideline for a moderate pace is that while you are exercising you should be able to talk but not sing.

Starting an exercise program is not easy, especially if you have a lot of fatigue. Following are some tips to get you started:

• Talk to your doctor about exercise. Before you start to make sure you don’t have any health conditions that might interfere with exercise. He or she may be able to refer you to a physical therapist or a physical medicine specialist who can help you develop an appropriate exercise program.

• Start slow! Exercise at a moderate pace for a short period of time. Maybe you feel you can only exercise for 2-3 minutes at a time – that’s OK! Schedule 2-3 minutes of exercise every other day, and gradually increase the length and the frequency of the exercise. Keep in mind that you don’t have to do your exercise in one long session; exercising in short bouts throughout the day also improves fitness.

• Wear appropriate, comfortable clothes and shoes while exercising, and drink plenty of water.

• Set realistic short and long-term goals. For the amount of exercise you want to do, and reward yourself for meeting your goals. For example, if your goal is to do a 5-minute walk on four days this week, reward yourself with something like a relaxing bubble bath or renting your favorite movie.

• Find an exercise buddy. Having someone who can encourage you when you don’t feel like exercising can provide that extra push you need to help you achieve your exercise goals.
If these thoughts sound familiar to you, you are not alone. Having ovarian cancer is a stressful experience, and the ways you have previously coped with problems may not work as well when you are confronting a serious disease and difficult treatment. Many women with ovarian cancer report psychological distress; studies have found higher levels of anxiety and depression among women with ovarian cancer than among women who do not have cancer.

What Should You Do?
A good place to start is to talk about your worries and distress with a good friend or family member, or perhaps, you might consider joining a cancer support group. While you probably have many friends who want to help you, keep in mind that not everybody is a skilled listener. Some people may try to tell you that you shouldn’t focus on your problems, that you need to have a positive attitude and be hopeful.

While hope and a positive attitude are good things, it is important to address the underlying issues that are contributing to your negative mood, to help you gain more control over your feelings. All of your feelings about your cancer experience are real and valid, including negative feelings. Try to find a confidante who can really listen to you talk about how you are feeling, rather than telling you how you should be feeling!

In addition to talking about your distress, a number of other self-help techniques may help you deal with distress.

Here are some for you to try:
Relaxation exercises: There are several relaxation techniques that, with practice, can help relieve your anxiety and improve your mood. Relaxation exercises generally involve deep breathing while imagining pleasant scenes or memories (guided imagery) or systematically tensing and relaxing muscles (progressive muscle relaxation). There are a number of books and tapes that can help you learn and practice relaxation exercises.

Exercise: Moderate exercise like brisk walking can also be helpful in managing stress and improving mood, but be sure to talk to your doctor to make sure that exercise is appropriate for you. See the section on fatigue for more information on exercise.

Get out and do something fun! Scheduling activities you enjoy, even when you’re feeling down, can help improve your mood by distracting you from the stress you’re experiencing. The activities don’t have to be complicated or tiring, just simple things that you usually enjoy but haven’t done as much since you got sick. For example, you could meet a friend for a cup of coffee, call a friend you haven’t seen in a while, or go to the store and buy yourself some flowers. Picking activities that would force you to do something intentional and active will be more likely to improve your mood than passive activities such as watching TV. Put your activities on a calendar or schedule so that you make sure you do them.
When More Help Is Needed

Sometimes women with ovarian cancer experience distress that is serious enough to warrant treatment. This is particularly true for women who have had episodes of depression or anxiety in the past, or whose physical symptoms are severe.

If you find you are experiencing symptoms like sadness and depression, feeling worthless, a lack of enjoyment of activities that you usually find pleasurable, excessive crying, or feeling sad and depressed most days for two weeks or more, you should discuss this with your doctor or a mental health professional.

If you find yourself thinking about hurting yourself or that you would be better off dead, you should talk to your doctor or call a local mental health crisis center right away.

You should also seek help if you find that your worries or any symptoms you are having are interfering with your usual activities or your relationships with the people close to you. For example, if you are feeling so anxious about leaving the house that you can’t work or participate in social activities you usually enjoy, you may have an anxiety disorder that needs further treatment.

Many cancer patients have found psychotherapy to be helpful; sometimes talking with an objective professional can be just the thing to help you gain the perspective and strength you need to cope with your particular situation. Your doctor may be able to recommend someone; you also can consult the websites listed in this booklet. There are proven treatments to help people deal with depression and anxiety; both medication and psychological or behavioral treatments have been found to be effective in relieving distress in cancer patients.

If your doctor prescribes medication, be sure to take the medication as directed by your doctor. These medications often take six weeks or more to start to work. If you find after giving the medication time to work, that it is not helping you or it is causing undesirable side effects, talk to your doctor. There are many different kinds of medication to help people with symptoms of psychological distress. Sometimes it takes a little while to find the one that works best for you.
The following list includes self-help books that may assist in teaching skills to manage stress. If you are experiencing clinical levels of distress, you may need to see a mental health professional. The websites listed provide information about qualified mental health professionals in your area.

**Stress Management/Relaxation**


**Mood Management**


**Websites**

*[www.apos-society.org](http://www.apos-society.org)*
The website for the American Psychosocial Oncology Society (APOS) offers a link to a referral helpline for individuals facing cancer and for caregivers. The referral program provides local counseling and support services throughout the United States, including psychiatrists, psychologists, nurses, and social workers trained to manage cancer-related distress.

*[www.aamft.org](http://www.aamft.org)*
The website for The American Association for Marriage and Family Therapists provides access to a searchable database for locating licensed marriage and family therapists. Under the heading “Public,” click on “Locate a Family Therapist Near You.”

*[www.nationalregister.org](http://www.nationalregister.org)*
This website for the National Register of Health Service Providers in Psychology provides a searchable database for locating doctoral level psychologists throughout the United States and Canada. After accessing the website, click on the link under “Find a Psychologist.” Begin searching by clicking on “Public.”
Financial concerns can be a major source of stress for women diagnosed with ovarian cancer. Financial issues can be related to employment, health insurance and travel and hotel expenses if you choose to travel for some of your treatment. There may be some steps you can take to minimize some of the financial stress.

**Employment**

If you are currently employed, you may wonder how your diagnosis and treatment will affect your job and what impact this may have on co-workers. A diagnosis of cancer is considered a “disability” under the 1990 Americans with Disabilities Act (ADA). This law covers employees of the legislative branch of the U.S. Government, state and local government entities, employment agencies, labor unions and employers with more than 15 employees.

Under the ADA, employers are required to provide reasonable accommodation to employees with known disabilities, as long as they are qualified for the job. The ADA requires the employee to notify her employer of her disability and the need for accommodation in the workplace.

Think about what kind of accommodations you may need at your workplace. Most women will need time to recover from initial surgery for ovarian cancer. Many women with newly diagnosed ovarian cancer will also receive chemotherapy every 3-4 weeks for several months. If your treatment plan involves receiving chemotherapy, consider getting your chemotherapy on Fridays so that you have the weekend to rest and recover.

You also may want to request working fewer hours on the Monday and Tuesday following your chemotherapy and making up the time in the weeks between chemotherapy cycles or at a later time. Requests for reasonable accommodations at work may include modifying work schedules to include flexible hours; time-off for medical treatments; temporary part-time work; job sharing; taking leave without pay; or working from home. Your employer will need to evaluate your particular situation to determine what can be done.

It is a good idea for you to check with the personnel or human resources department at your workplace to find out more about specific employment policies that may apply to you. You should be aware that certain situations exist in which the employer may not be required to provide accommodations. In addition, small employers are not subject to federal law (in these situations, check with your state’s agencies, congressional representatives or senator to find out more about what policies are in place to protect you).

For more information on the ADA, check with your local American Cancer Society office or on the web at [www.cancer.org](http://www.cancer.org) or the National Coalition for Cancer Survivorship at [www.canceradvocacy.org](http://www.canceradvocacy.org).

Another federal law is the Family and Medical Leave Act of 1993 (FMLA). This law, along with certain state laws, stipulates that employees may take up to 12 weeks of medical leave during a 12-month period. The leave can be taken all at once or can be taken in different time allotments, depending
on what the employer and employee agree upon. The FMLA does not require that employees receive salaries during medical leave; the law does provide that employees retain their job positions and all benefits. Some employers may also provide other employee benefits during this time. Certain eligibility requirements exist for FMLA so check with the personnel/human resources department at your workplace to find out more details about your company’s leave policies.

If you have a caregiver who is a family member (defined as a spouse, parents, or adult children), he/she may also be eligible for family medical leave. You may want to plan on having your caregiver’s assistance while you are recovering from surgery and/or during the times you receive chemotherapy. Your family member caregiver should check with the personnel/human resources department at his/her workplace for more information.

If you are considering taking family medical leave, keep in mind that the FMLA leave of 12 weeks total will not cover the entire time necessary for surgery and standard chemotherapy for most women with newly diagnosed ovarian cancer (recovery from surgery can take up to 4-6 weeks, and 6 cycles of chemotherapy typically encompasses 18 weeks). If possible, see if you can take your medical leave in 1-week increments structured around your chemotherapy appointments (day of treatment + several days to recover). This strategy may allow you to more effectively use your medical leave.
Insurance
A lot of attention has been given to concerns about health insurance coverage for individuals diagnosed with cancer. Specific areas of concern include restrictions on where you can receive your cancer treatment, maximum dollar amount of insurance coverage provided, and fear of losing coverage.

The key to managing these concerns is to understand your insurance plan.

There are some things you can do to help de-mystify confusion about health insurance.

If you have insurance coverage through a group health insurance plan offered by your employer (or your spouse’s employer):

• Ask your plan’s administrator or benefits representative for materials (e.g. booklet or website) that describes your insurance plan
• Obtain a copy of the plan from the insurer
• Read these documents very carefully, paying particular attention to exclusion policies
• Find out whether special requirements exist, i.e. pre-certification, claim submissions, extra costs for going out-of-network for doctors or hospitals, inpatient vs. outpatient coverage for certain treatments
• Find out whether clinical trials are covered (understand your plan’s definition of “experimental” or “investigational” treatment)
• Be aware that federal and state laws exist to protect you from losing your insurance coverage

If you have insurance through a government-sponsored program such as Medicare or Medicaid, you can log on to www.cms.hhs.gov or call (410) 786-3000 for more information.

If you do not have insurance coverage call the American Cancer Society office for available resources: 1-800-227-2345 (1-800-ACS-2345).

Since understanding and working with insurance plans can be extremely time-consuming and detail-oriented, ask a family member to help you manage this process; it is often helpful to have another person review the paperwork.

Following are recommended ways to help you manage your insurance concerns:

• Submit claims in a timely fashion
• Keep accurate records
• Use an accountant’s worksheet to keep records straight
• Make copies of ALL bills
• Submit your claims in the correct order if you are covered under 2 plans
• If your claim is denied:
  - Send the claim back again with copies of documentation
  - Do not take no for an answer (persistence may pay off — could be miscoding or verification that appropriate referral was made)
  - Make sure your total charges agree with the total amount of your bill
  - If needed, justify doctor’s charges (ask MD to write a letter)
  - Ask for formal review of claim
  - Know which benefits are mandated by your state
  - Use customer helpline, get the name of service representative/claims examiner and the date of your call
  - Consider assigning these tasks (what to do if claim is denied) to a family member to minimize your stress
Keep a notebook where you can jot down questions that come up, along with the answers you receive and the person’s name/affiliation who answers your questions (e.g. insurance representative, benefits representative, etc).

Social Security Disability Insurance
Some women may be unable to work due to progression of their ovarian cancer or because of continuous cancer treatment. These women may be eligible for Social Security Disability Insurance (SSDI).

The SSDI pays monthly disability benefits to individuals who meet strict eligibility criteria. Specifically, Social Security must determine a woman’s inability to work as she did before due to her ovarian cancer as well as her inability to work for at least 12 months. Monthly benefits are based upon the individual’s income history. To learn more about Social Security Disability Insurance and whether you qualify, contact Social Security at 1-800-772-1213 or visit the website at www.ssa.gov and click “Disability and SSI.”

Travel and Lodging
If you need to travel beyond your local area to receive treatment or get a second opinion, costs associated with travel (gasoline, airfare) and lodging (hotel and food) can add up quickly. If geography is a limiting factor and there are no gynecologic oncologists in your area, you may have to travel to have your surgery performed by a gynecologic oncologist. Your gynecologic oncologist may be able to coordinate your chemotherapy with a medical oncologist in your hometown.

Many top cancer centers are accustomed to out-of-town patients and have personnel on staff who assist with travel and lodging information and arrangements. These cancer centers often have special arrangements for discounted airfare, car rental, and hotel rooms. Some centers even have onsite housing available.

Other resources include:

The American Cancer Society Hope Lodge Program
1–800–227–2345 (1–800–ACS–2345)
www.cancer.org

National Association of Hospital Hospitality Houses
1-800-542-9730
www.nahhh.org

Delta SkyWish in conjunction with the United Way
1-800-892-2757, ext. 285, M-F 9am-5pm

Air Care Alliance
1-888-260-9707
www.aircareall.org

Corporate Angel Network
1-914-328-1313, M-F 8:30am - 4:30pm EST

Mercy Medical Airlift’s National Patient Air Transport Helpline
1-800-296-1217
www.patienttravel.org

Social Security Disability Insurance

If you are considering a clinical trial but the location of the trial is far from where you live, ask the sponsor of the trial or check with your insurance plan to see if either will cover part/all of your travel costs.
For many women with ovarian cancer, life after cancer includes learning to cope with serious, long-term sexual problems. In a survey of 200 survivors of ovarian cancer, more than half of the women reported that their sex lives had been negatively affected by cancer or its treatment, and 75% described their sex lives as poor to adequate. Women with ovarian cancer report a range of sexual difficulties; decreased libido, vaginal dryness, and pain during intercourse are the most prevalent. These problems can arise from multiple causes, including surgical or treatment-related menopause, disturbed body image, and increased psychological distress.

Many patients are reluctant to ask their healthcare team questions or mention sexual problems. Gather up your courage and ask anyway! Your healthcare provider can provide information about the possible causes of sexual problems and changes, and may have suggestions for how you can overcome them. You and your partner may decide you would also benefit from working with a sex therapist. The American Association of Sex Educators, Counselors, and Therapists (www.aasect.org) can assist with identifying a credentialed sex therapy professional.

There are also several excellent self-help books on the topic of sexual function for cancer survivors. The booklet “Ovarian Cancer: Sexuality and Intimacy” is available for free by contacting The National Ovarian Cancer Coalition at 1-888-OVARIAN or www.ovarian.org. The American Cancer Society has published two books on sexuality after cancer, one for men and one for women (Sexuality & Cancer: For the Woman Who Has Cancer and Her Partner; for a free copy call the American Cancer Society at 1-800-ACS-2345). The book Sexuality and Fertility After Cancer by Leslie R. Schover, Ph.D. (John Wiley & Sons, 1997) is also an excellent resource.

A diagnosis of ovarian cancer will affect a woman’s relationships with members of her family.

Family and friends can be an important source of emotional support. If you have children, you may wonder how much about your diagnosis and treatment to tell them. The American Cancer Society’s (ACS) website (www.cancer.org) offers excellent information about how to talk to children about a cancer diagnosis in the family. In addition, the ACS offers good advice for how friends and family can be there to help support you during this time, along with how you can talk to friends and family members about your diagnosis.

If your cancer is the result of inherited cancer syndromes such as BRCA1/2, or you are considering genetic testing, you may be wondering how to discuss this with family members and the implications of this information. The National Cancer Institute offers patient education materials such as “Understanding Gene Testing” at www.cancer.gov or at 1-800-422-6237. You may also want to contact The Gilda Radner Familial Ovarian Cancer Registry at 1-800-682-7426.
All women with ovarian cancer face concerns about the end of life. While women are living longer thanks to new treatments, thinking about the possibility of death is totally normal once you have been given this diagnosis.

Some women may worry about dying even before they have surgery, while others don’t start thinking about it until they have taken multiple chemotherapy regimens.

What is important is that you devote your energy to this issue when the time is right for you.

While you may think this is a difficult topic to discuss with your loved ones, it will be much more difficult if you have not discussed your preferences with them. Usually once the subject is discussed, everyone feels a great sense of relief.

Advance Directive

An “Advance Directive” is any 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. You have many options for these instructions. You can create a living will, which is a document that explains your wishes for medical care when you cannot make your own decisions.

You can also name a surrogate decision maker, someone you identify and trust to make those 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 certain states, this person can only make decisions for the patient at the end of her life. Such important considerations may involve the wish for life-sustaining treatment or hospice consultation.
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 such a document, you can be sure that your wishes are met and can also 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 are not put on a breathing machine if you stop breathing and 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 are often reluctant to discuss this issue with their physician as they feel DNR means they will no longer receive appropriate medical care. This is far from the truth. This order just means that extraordinary measures such as intubation (being put on a breathing machine) or CPR will not be performed. It does not mean that your medical condition will be ignored or that you will be given sub-standard care. As with the Advance Directive, a DNR order gives you control in what may be a very difficult situation for you and your family. It ensures that your wishes are respected. You might not be ready to think about DNR right now. Nothing is wrong with this. Just be aware that it is an option to give you more control of your medical situation should the circumstances arise.

### Considering Hospice

Once you decide to no longer receive active treatment, the focus shifts to providing comfort care. The goal is to help take care of any symptoms you may have, such as nausea or pain, and keep you as comfortable as possible. Quality of days rather than quantity is the priority.

Hospice care focuses on patients who are terminally ill. This team of healthcare workers includes physicians, nurses, social workers, pastoral care workers, and volunteers who are experts in end of life care.

Hospice can take place in a facility, such as part of a hospital, or in a free-standing building. It can also be in your home. This requires that someone stay with you at all times. It does not always have to be a relative and does not need to be the same person all the time. People often prefer home hospice, as the healthcare team can come to their home to help, and they can remain in a familiar and comfortable setting.

There is no right or wrong here. What really matters is that you spend your time in the setting you choose. Hospice is about keeping you comfortable and helping you feel loved during this time.

In addition to helping you, hospice is also an invaluable service to your loved ones. Hospice workers help not only with medical care, but also provide emotional support to you and your loved ones. They are trained to help you deal with the physical, emotional, and even spiritual issues which may arise.
Complementary and Alternative Medicine

People are often confused about the differences between complementary and alternative medicine. Complementary medicine makes use of non-conventional treatment modalities, such as acupuncture, in combination with conventional or standard treatment. Alternative medicine, on the other hand, refers to a treatment modality that is used in place of standard treatment. By definition, alternative treatments are not integrated as part of conventional medicine.

Many physicians are now replacing the term “Complementary and Alternative Medicine” (CAM) with that of Integrative Medicine. Rather than focusing on specific non-conventional treatment modalities, this term describes an approach to treating patients. It strives to integrate the best complementary and conventional modalities using a multidisciplinary care approach.

So what does Integrative Medicine mean for you? Several recent studies reveal that up to 90% of ovarian cancer patients already combine some type of complementary medicine with the treatment prescribed by their physician. Common approaches include massage and other touch therapies, yoga and tai chi, art therapies, meditation and relaxation therapy, as well as acupuncture. These treatments may help reduce side effects of cancer therapy, improve quality of life, enhance self-care, and reduce pain, anxiety, and depression.

Caution should be given to alternative treatments which you might combine with standard therapies.

Often there is very little published information about such therapies, and such interventions may, in fact, interfere with the treatment prescribed by your physician. It is important to discuss any and all medications you are taking with your physician, as some alternative treatments might decrease the efficacy of your chemotherapy.

Other treatments could potentially make you bleed more, a big concern if you are going to have surgery. Depending upon your kidney and liver function, some alternative treatments could have difficulty being metabolized by your body. This could lead to high and potentially dangerous levels of these drugs in your body.

The more information you can get about all the therapies you are considering, the more educated your decision will be and the less the risk you will be taking in terms of possible drug interactions or side effects. If your doctor cannot advise you about these therapies, ask him/her to recommend a registered pharmacist who is knowledgeable about these issues. None of us would want to take a therapy that could potentially harm or lessen chances of a cure!

Nutrition

The most meaningful advice about nutrition and cancer is something your mother probably told you long ago: “Eat a healthy and balanced diet. Eat plenty of fruits and vegetables. Drink lots of water.”

These concepts work well for women with cancer and those without. Make sure you have plenty of fruits, vegetables, protein, and fiber in your diet. Drink lots of water, especially if you are receiving chemotherapy, as this helps “flush out” your system. Many oncologists recommend that you take a...
daily multivitamin. This is fine, as long as it does not upset your stomach. Do not take megadoses of vitamins, as this may be dangerous. Vitamins A, D, E and K are fat soluble, meaning they can stay in your system and build up to dangerous levels if your body cannot metabolize them. Moderation in terms of vitamins is the best approach.

Ask your doctor to recommend a nutritionist to you. The nutritionist will help you plan a healthy diet whether you have had surgery or are undergoing chemotherapy. The nutritionist will also make sure you get the nutrients you need.

Women with ovarian cancer can have special dietary needs if they have had extensive bowel surgery or have a partial bowel obstruction. Certain chemotherapy drugs can make you very nauseated and unable to eat. The input of the nutritionist is critical in these situations. You will become stronger and feel better if your nutrition is the best it can be.

**Spirituality**

When people hear the term “spirituality” they often think about religion. Spirituality has been defined as a person’s sense of peace, purpose, and connection to other people and how a person views the meaning of life.

A person’s religious practice may be a way of expressing her spirituality although it is important to acknowledge that a woman may be very spiritual but not religious. Either way, a woman’s spiritual perspective may help her cope with a life-changing event such as a diagnosis of ovarian cancer. Cancer affects every part of a woman’s life - life at home, at work, with friends and with family. Some women may want their doctors to discuss spiritual concerns with them, while others may not. If your spiritual or religious beliefs influence the manner in which you make medical decisions, you should let your healthcare team know. You should expect that your doctor will respect your religious or spiritual views, regardless of whether you consider yourself to be spiritual/religious or not.

While researchers do not know for sure if spiritual and religious well-being are associated with a better quality of life, some experts believe that it may help a woman’s positive mental attitude. This, in turn, may help her better cope with the disease and treatment process.

If religion or spiritual practices such as meditation are a normal part of your life, then you may find that you will seek this support on a regular basis during the diagnosis and treatment process. Likewise, if you want to speak to someone about spiritual or religious concerns but do not have access to these individuals, let your hospital social worker know or speak with a member of your healthcare team to ask how you can contact a hospital chaplain, clergy, rabbi or support group that addresses spiritual concerns during illness.

In times of crisis, many women may turn to their place of worship for spiritual and social support to help cope with the day-to-day concerns of living with ovarian cancer.

Women may find strength in their religion or spiritual outlook; it may help them connect emotionally to other people in turn helping them cope with their disease and begin the healing process.
Cancer diagnosis and treatment can be overwhelming for any person and it can be easy to lose track of where and when decisions need to be made. In the midst of learning all of the terminology, anatomy and scientific information that comes with undergoing surgery and chemotherapy, some women may prefer that their physicians make all the major medical decisions. Still other women may want to question every aspect of their medical care and challenge their healthcare team on even minor issues.


It is important for women to understand that often, in oncology, there may be no “right answers” - even the best doctors may not agree upon certain issues related to cancer treatment. It is also important for women to understand that it is each woman’s right to decide upon all aspects of her medical care and to have access to her medical records and test results.

Living with cancer involves making major decisions. Broadly speaking, decisions will need to be made:

- **At the time of diagnosis and surgery** (Who will do the surgery? Where will it be done? Does the pathology need to be confirmed?)
- **At the time of treatment planning** (Where to receive chemotherapy? Is there a study available? How many cycles?)
- **During follow-up** (CA 125 results, maintenance issues)
- **If/when CA 125 increases or recurrence is found on follow-up** (More chemotherapy? Another surgery?)
- **What to do if the cancer is not responding to the chemotherapy** (Change chemotherapies? Look for clinical trials? Get a second opinion/visit a different hospital?)
- **When to stop treatment** (End of life issues?)

Your Role in the Decision-Making Process
Your healthcare team is a diverse group of people dedicated to giving you the best care possible while you fight ovarian cancer. In addition to physicians and nurses, there are many other people working to take care of you. If you haven’t met the people listed here and feel that you should have, ask your doctor to introduce you. Each individual has expertise in an area which could be a big help to you.

**Case Manager**
Depending upon the organization of your hospital, the case manager is the individual assigned specifically to you while you are hospitalized. This person helps facilitate your discharge from the hospital, sets up outpatient services you need, and helps coordinate insurance issues. He or she deals with such practical issues as getting a home health nurse, renting a wheelchair, or setting up physical therapy appointments. Your case manager should work with you to help anticipate and meet needs you will have after you leave the hospital.

**Ostomy Nurse**
This individual has received special training in wound care and the care of ostomies (colostomies, urostomies, etc). His or her job is to teach you, usually in conjunction with floor nurses, how to care for your ostomy. The goal is to help you feel comfortable with this change in your life, whether it is temporary or permanent. Ostomy nurses often have a network of patients who volunteer to speak with other patients about to undergo ostomy surgery. Talking with someone in your situation is often very helpful in addressing and allaying your concerns.

**Patient Advocate**
This is again institution-dependent. This person is your advocate. You should contact him/her with any concerns that cannot be addressed by other members of your healthcare team. The advocate can help facilitate obtaining pathology reports, reschedule chemotherapy administration if your appointment won’t work for you, or just listen to concerns you have about your care. Advocates know the “ins and outs” of the institution, and function to help with any problems you might have.

**Nutritionist**
The nutritionist can provide valuable advice about your diet and nutritional needs. Nutritionists who specialize in working with cancer patients have expertise in dealing with post-operative patients, especially those with ostomies, as well as patients with special nutritional needs. Most institutions have nutritionists on staff.

**Social Worker**
The Social Worker often works in conjunction with the case manager and patient advocate to meet any practical needs you might have. This person may help with financial concerns, job-related issues, and establishing advance directives. Lodging questions, transportation issues, and even meal tickets are usually taken care of by the Social Worker.
**Psychiatrist**
Most hospitals have a psychiatrist on staff who helps patients deal with the emotional aspects of a cancer diagnosis and cancer treatment. These physicians often work together with social workers to provide support and treatment for such issues as depression and anxiety. They may also run support groups in your hospital to help women with ovarian cancer deal with such issues.

**Physical and Occupational Therapist**
Physical and Occupational Therapists can be invaluable to patients recovering from surgery, experiencing cancer-related symptoms, or having treatment-related side effects. They can help with physical issues such as walking, and with occupational-type issues such as performing household tasks after recovering from an extensive surgery. Services are usually offered on both an inpatient and outpatient basis.

**The Importance of a Gynecologic Oncologist**
It cannot be emphasized enough how important it is to be under the care of a gynecologic oncologist. This physician is specially trained to take care of women with gynecologic cancers, including those with ovarian cancer. Most gynecologic oncologists perform surgery and administer chemotherapy. They also provide surveillance once treatment has been completed. Studies show that women who have their surgery performed by a gynecologic oncologist live longer than those who do not. We encourage all women to seek the care of a gynecologic oncologist if they are concerned about having a gynecologic cancer.
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Dr. Diane C. Bodurka is an Associate Professor in the Department of Gynecologic Oncology at M. D. Anderson Cancer Center. She is also Program Director of the Gynecologic Oncology Graduate Education Training Program, the largest gynecologic oncology training program in the United States. Dr. Bodurka's major clinical interests include ovarian cancer and health services research, particularly quality of life issues, patient preferences, and outcomes analyses. She has studied depression in ovarian cancer patients and has been awarded two grants to study quality of life and patient preferences for treatment outcomes in women at increased risk of breast and ovarian cancer, as well as in women receiving high-dose versus standard chemotherapy. Dr. Bodurka received her undergraduate degree in Psychobiology from The University of California, Los Angeles. She earned her MD degree from Georgetown University School of Medicine in 1990. She went on to complete her internship and residency in Obstetrics and Gynecology, where she was honored as both Administrative Chief Resident and Best Teaching Resident. She moved on to M. D. Anderson that year as a Junior Faculty Associate, where she completed a 2-year fellowship in Gynecologic Oncology. She is currently a Master's Candidate in Health Services Organization at The University of Texas School of Public Health.

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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.

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