



# QUALITY OF LIFE ISSUES





## 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.

### OUR MISSION

To save lives through the prevention and cure of ovarian cancer and to improve the quality of life for survivors and their caregivers.

### OUR VISION

We envision a future where no woman ever loses her life to ovarian cancer.

### OUR VALUES

Connection, inclusivity, perseverance, authenticity, compassion, empowerment.

**For more information about the NOCC, visit [ovarian.org](http://ovarian.org) or call 1-888-OVARIAN (1-888-682-7426).**

## 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 feminine, and overcoming fatigue. Women want to know the effects of therapy on quality of life (QOL), and deserve to have this information.

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

With support and encouragement,

**NATIONAL OVARIAN CANCER COALITION**



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## TREATMENT-RELATED SIDE EFFECTS

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 your specific treatment plan. The key to proactively managing side effects begins with good communication with your 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 under report 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 kept in one place.

### 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.

### 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 frequently 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?

### 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](http://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](http://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](http://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.

### 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 (800-826-0826 or [uoa.org](http://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 both the 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 dietitians 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 ([cancer.gov](http://cancer.gov)) and the American Cancer Society ([cancer.org](http://cancer.org)) also provide information about eating and nutrition for cancer patients.

## IF YOU ARE EXPERIENCING DIFFICULTY WITH BALANCE OR WALKING, 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

## 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

## 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 why moderate exercise decreases fatigue for some people.

### 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

### Starting an exercise program is not easy, especially if you have a lot of fatigue. Here 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. They 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 overall 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 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 a 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.

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.

## DEPRESSION, ANXIETY AND DISTRESS

**“I just don’t seem to enjoy things like I used to. I used to love a good movie – now they all seem to bore me and I just feel like sleeping.”**

**“I can’t seem to stop thinking about the cancer and what might happen. Even when I’m with other people and I’m having a good time, worries about the cancer pop into my head.”**

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 or 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.

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.



## RESOURCES

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

#### **The Relaxation & Stress Reduction Workbook**

(August 1998). By Martha Davis, Elizabeth Robbins Eschelman, Matthew McKay, Matt McKay, Beth Eshelman (4th workbook edition).

#### **Full Catastrophe Living: Using the Wisdom of Your Body and Mind**

**to Face Stress, Pain, and Illness** (1990). By Jon Kabat-Zinn.

#### **Your Perfect Right: A Guide to Assertive Living**

(October 1995). By Robert E. Alberti & Michael L. Emmons (25th anniversary edition).

#### **The Feeling Good Handbook**

(May, 1999). By David Burns (revised edition).

**Learned Optimism** (March 1998). By Martin E. P. Seligman (reissue edition). Also available in audio cassette.

#### **Mood Management Mind over Mood: Change How You Feel by Changing the Way You Think**

(1995). By Dennis Greenberger & Christine Padesky

### WEBSITES

**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.

**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."

**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

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.

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 [canceradvocacy.org](http://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

## 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 two 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

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 demystify 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](http://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: 800-227-2345 (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.



**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 800-772-1213 or visit the website at [www.ssa.gov](http://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 and 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 800-227-2345 (ACS-2345) or [cancer.org](http://cancer.org)
- National Association of Hospital Hospitality Houses 800-542-9730 or [nahhh.org](http://nahhh.org)
- Delta SkyWish in conjunction with the United Way 800-892-2757, ext. 285, M-F 9 a.m. — 5 p.m.
- Air Care Alliance 888-260-9707 or [aircareall.org](http://aircareall.org)
- Corporate Angel Network 914-328-1313, M-F 8:30 a.m. – 4:30 p.m. EST
- Mercy Medical Airlifts National Patient Air Transport Helpline 800-296-1217 or [patienttravel.org](http://patienttravel.org)



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.

## END OF LIFE CONCERNS

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 health care 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.

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.

### SEXUALITY & INTIMACY

Women who have battled ovarian cancer often experience long-term side effects to their reproductive health. Common problems include menopause symptoms, sexual problems, and infertility. For many women, these changes have a major impact on quality of life. Although we may not be able to repair all the damage done by cancer treatment, many of the physical symptoms and negative emotions can be overcome so that women can live more complete lives again.

### HOT FLASHES, VAGINAL DRYNESS, AND OTHER MENOPAUSAL MENACES

As women are reminded when diagnosed with ovarian cancer, the ovaries produce the hormones that control a woman's menstrual cycle. A few younger women with less common types of ovarian cancer (germ cell tumors, borderline tumors, very early stage,

low grade epithelial tumors) may get to keep one ovary. If they need chemotherapy, it is often a type that does minimal damage to that remaining ovary, so that menstrual cycles return to normal within several months. For these women, menopause is not an immediate problem.

The great majority of ovarian cancer survivors, however, will be menopausal after treatment. Many women have already reached menopause before ovarian cancer is discovered. The average age of menopause for American women is 51. After receiving a diagnosis of ovarian cancer, women tend to be very concerned about taking hormone replacement.

A small group of women get ovarian cancer before the age of menopause. For this group, their cancer treatment will typically put them suddenly into menopause, which may worsen their menopause symptoms.

Most women will have had both ovaries removed in surgery. Ovaries can also be damaged easily by radiation to the pelvic area or by high doses of chemotherapy. Without the ovarian hormone estrogen, a woman could be at increased risk over the years for heart disease and osteoporosis (loss of bone strength).

More immediately she may notice hot flashes - a sensation of facial flushing and body heat, often with sudden sweating.

Hot flashes are especially common at night, when the brain normally produces a messenger chemical that tells the ovaries to make estrogen. With no ovaries to respond, the brain pumps out this messenger, causing the hot flash.

Another side effect of estrogen loss is vaginal dryness.

Estrogen helps keep the vaginal walls supplied with tiny blood vessels. When a woman becomes sexually excited, these vessels fill with extra blood. The vagina deepens and its lining produces a clear fluid that makes the walls slippery, ready for intercourse.



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.



Without estrogen, some of the blood supply is lost, and even with sexual caressing or fantasy, a woman finds that her vagina stays somewhat dry and tight. These changes may worsen over time, until for some women, intercourse becomes painful. Tiny tears in the vaginal lining from the friction of intercourse can cause burning and even spotting of blood after sex. Estrogen also has mild effects on mood, although depression is truly not a common effect of menopause.

Progesterone, the second ovarian hormone that controls menstruation, actually can make women feel blue around the time they get their period - something few of us miss! Scientists think estrogen also helps protect short-term memory, but it is not clear yet whether early menopause has long-term effects on women's ability to recall names of people at a party, remember lists of errands, or call their children by the correct first names. That does not stop us from blaming these daily life errors on menopause, however, whether we call it chemobrain or a senior moment.

## TAMING HOT FLASHES

Although hot flashes can be annoying and embarrassing, for many women they decrease within the first months or years after reaching menopause. They seem to be especially frequent and severe in women who have a sudden menopause because of their cancer treatment. If hot flashes are disturbing your sleep, they can contribute to you being tired and irritable during the day.

The major ways to decrease hot flashes include:

- Using estrogen replacement hormones in pill or patch form
- Taking low doses of some antidepressants
- Learning relaxation and deep breathing techniques
- Using some "tricks" to avoid triggering hot flashes or to minimize the discomfort they cause

### Estrogen Replacement

Taking estrogen in the form of a pill or patch is the fastest and most effective way to get rid of hot flashes. Estrogen replacement also unquestionably helps keep women's bones strong, preventing broken hips or chronic back pain from osteoporosis. Most oncologists do not believe that estrogen replacement therapy increases the risk of ovarian cancer coming back, particularly in women who get ovarian cancer in their postmenopausal years.

However, young women whose ovarian cancer is related to mutations in the BRCA genes may increase their risk of breast cancer by taking estrogen. Women who have had any kind of cancer in the reproductive system tend to shy away from taking estrogen, and the findings of the Women's Health Initiative - that estrogen increases breast cancer and uterine cancer risk without preventing heart disease - have made many reconsider taking this hormone.

### Antidepressants for Hot Flashes

Many women have taken drugs like the clonidine patch or Bellergal to counteract hot flashes. These remedies have only a mild positive effect and also bring many unpleasant side effects.

Studies have shown that some of the newer antidepressants, including ones called "SSRIs" like Prozac®, Paxil®, or Zoloft®, and ones with even fewer side effects, like Effexor®, can reduce hot flashes as much as 60%. The dose required is lower than the dose typically used to treat depression.

Still, the SSRIs can cause dry mouth and dizziness on standing. More importantly, they may reduce a woman's desire for sex somewhat, and make it more difficult (or even impossible) for her to reach orgasm. Regardless, if you have troublesome hot flashes, these medications are worth a try.

If you encounter sexual side effects, try switching from one type to another. Some of the newer medications with fewer sexual side effects may be more expensive, however.

### Relaxation and Deep Breathing

A number of research studies have shown that women can learn to use relaxation and deep breathing techniques to tame their own hot flashes, reducing both their frequency and intensity.

Here are some relaxation techniques to practice:

- Practice breathing from your stomach. Inhale through your nose, and exhale slowly from your mouth. When you are breathing deeply and slowly, your stomach will rise and fall as you inhale and exhale.
- Try taking 6 to 8 slow, deep breaths each minute (that means about 1 every 10 seconds).
- It may help if you think of a special word or two each time you exhale. Words that some women like include: "calm down," "stay cool," "peace," "relax," or a favorite phrase from a prayer or poem.
- Practice your deep breathing at least twice a day, and use it when you feel a flash coming on.

It also may help to practice some deeper muscle relaxation routines several times a week. One method is to tense up a part of your body, observe the tension, and then let those muscles go loose, observing yourself again. Start this pattern with your face and neck, and then repeat it going down your body.

Look for relaxation audio tapes or CDs at a bookstore, media store, or on the Internet. Many tapes have soothing music.

Your environment also can make a difference. Heat is a hot flash trigger. Keep room temperatures on the cool side, and consider having a fan. Try keeping a glass of cold water or juice nearby. At night you can even keep some ice water and a washcloth by the bed to soothe your face or throat. If you tend to wake up in a pool of sweat, have an extra towel or cotton sheet handy. Layered bed coverings give you the flexibility to take some off if a hot flash strikes. It also helps to keep a regular bedtime and waking time, to maximize good sleep.

Your clothes can even make a difference. To absorb the perspiration, get cotton bras and panties. Wear comfortable, loose layers of clothing that you can take off easily when the flashes come.

### VAGINAL DRYNESS CAN BE OVERCOME

Although vaginal dryness can make a woman dread sex instead of anticipating it with pleasure, there are several ways to potentially overcome the dryness and make intercourse pleasurable again:

- Use local estrogen replacement that affects only the vaginal area
- Use vaginal moisturizers and creams
- Adjust your lovemaking techniques
- Learn to relax tight vaginal muscles

### Vaginal Estrogen Replacement

There are at least two new ways to give estrogen directly to the vaginal lining and walls, but allowing very little of the hormone to get into the general bloodstream where it might increase a woman's risk of breast cancer. More of the estrogen might reach the uterus, however, with a very slight risk of increasing uterine cancer.

The Estring® looks like the rim of a diaphragm, but without the rubber cup attached. A very slowly released form of estrogen is stored inside of the ring. The ring can be put into your upper vagina by a gynecologist, or you can insert it yourself if you are comfortable with the idea. You wear it in your vagina for three months, while the estrogen is slowly released. The Estring® usually makes sex comfortable again, and in about half of women, improves problems with urinary control.

Vagifem® is an estrogen tablet that melts in the vagina, and has similar good effects, again with very little estrogen getting into the bloodstream. These local estrogens won't stop hot flashes but they will give most women excellent relief from vaginal dryness.

### Vaginal Lubricants and Moisturizers

If you want to avoid any type of estrogen, or your vaginal dryness is fairly mild, the newer vaginal lubricants and moisturizers on the market may be all that you need. The lubricant you choose should be water-based and should not contain oils or petroleum jelly (Vaseline). It should not be perfumed, since scents are one of the most common irritants on the delicate, genital tissue.

Gel lubricants tend to work best when they are thin liquids, similar to the body's natural lubrication. Old-fashioned gels, like K-Y Jelly or Surgilube, tend to be too thick, and dry out quickly. Large drugstores now carry a wider variety of lubricants. It is also easy to order lubricants over the Internet at sites like [www.drugstore.com](http://www.drugstore.com).

Some of the more popular liquid lubricants include Astroglide, Probe, KY Liquid, KY Silk-E, ID Glide, Liquid Silk, Slippery Stuff, Sylk, and Aqua Lube. Some websites with the best selection of lubricants also market other sexually explicit products, like videos or sex toys that some women may find offensive.

The following sites are pro-woman, will not put your name on x-rated mailing lists and have discreet packaging: [goodvibes.com](http://goodvibes.com), [evesgarden.com](http://evesgarden.com), and [xandria.com](http://xandria.com).

Knowing how to use a lubricant is another secret to success. Your partner can use a gel lubricant when caressing your vulva or vagina. Keep your lubricant next to you when you make love, so that you do not have to stop to go and get it. Putting on a lubricant can become a routine part of your lovemaking.

Ask your partner to spread it around your clitoris and vaginal entrance during foreplay. Spread some over the head of his penis when you are caressing him. Before penetration for intercourse, both the penis and the vaginal entrance should be lubricated to minimize friction and tightness.

A product called Replens is marketed as a vaginal moisturizer. It can be used in addition to water-based lubricants, which may help for severe dryness. Women with milder problems who use Replens may not need to add a water-based lubricant before lovemaking. Replens is meant to be used three times a week before bedtime. Replens is a special gel that helps the vaginal lining retain moisture. A woman inserts the gel into her vagina using a tampon-shaped applicator.

One study showed that after 12 weeks of regular Replens use, women who were in menopause had vaginal examinations similar to those of women taking estrogen. Replens improved the vagina's moisture, stretchiness, and acidity.

Besides making intercourse more comfortable, these changes could potentially help to prevent vaginal yeast infections. Some women dislike Replens because it increases their vaginal discharge. The amount of discharge tends to decrease after the first two weeks of use, so it is important to give Replens a chance. Replens is sold over the counter, without a prescription, but it is more expensive than other lubricants - costing somewhere around \$20 to \$25 a month.

### Changing Your Lovemaking Techniques

The more sexually aroused you become, the more natural lubrication your body will produce. As women get older, and particularly after menopause, it takes longer to get aroused. Spending more time on foreplay is important.

For many women with ovarian cancer, foreplay time may have become shorter. Some women have so much difficulty getting in the mood for sex that they subtly persuade their partner to "get it over with."

In some couples the partner has developed problems with erections. Foreplay may be focused on helping him get erect enough for intercourse, with little attention to the woman's needs.

Sometimes foreplay has just disappeared as sex became routine over the years. Not only for the sake of getting lubricated, but for your general pleasure, it is important to take time to enjoy touching yourself, and to give yourself a chance to get mentally aroused.

As mentioned earlier, you may feel weak or tired while undergoing cancer treatment. The position that you and your partner used in the past may not be comfortable or may be difficult for you as you are tired or weak. During this period you may want to try new positions for making love with your partner. A woman who has an ostomy may need to reduce pressure or discomfort at the colostomy site. In this situation, experimentation with your partner in various lovemaking positions may be necessary.

Most people have used the "missionary" position. You may be able to enjoy intercourse more now if you both lie facing each other or if you "spoon" (you lie on your side with your partner next to your back side). You might also feel better if you sit astride your partner - this can allow you to control the experience more and allow your partner to touch you more with his hands - which could provide more stimulation for making love.

### Relaxing Tight Vaginal Muscles

If a woman has had the experience of painful intercourse after her ovarian cancer treatment, she may tense the muscles surrounding the vaginal entrance involuntarily out of fear that intercourse is going to hurt again. This muscle tension makes the vaginal entrance tighter, increasing friction and irritation during penetration for intercourse. If you think this may be a problem for you, you can learn how to control these muscles, relaxing or tensing them at will.

The pubococcygeus, or "PC" muscle surrounds the outer third of the vaginal canal, closest to the entrance. It is connected to a sheet of muscle that also includes the anal sphincter, which helps us hold in bowel movements, and the outer urinary valve. When a woman squeezes to shut off the flow of her urine or to prevent a bowel movement, she is also contracting her PC vaginal muscle.

Once you know how to tighten your PC muscle, you can become aware of the contrasting feeling when it is tense versus when it is relaxed. Then you can practice relaxing the muscle in a controlled way. Next time that you urinate, notice the squeezing motion you use when you want to shut off the flow of urine. Try the squeeze when you are not urinating, but just sitting or lying comfortably. Can you feel a tensing at the entrance of your vagina? Even after pelvic surgery for ovarian cancer, most women have voluntary control over the PC muscle.

To check that you are tensing the right muscle, put a water-based lubricant on the tip of your finger or on a tampon with a rounded plastic applicator. Lie back on the bed with your knees up and apart, or try sitting against some pillows with your knees bent and open. Hold the lubricated finger or tampon at the entrance to your vagina.

If you are unsure of the exact location of the vaginal entrance, look at yourself in a hand mirror, for example a lighted make-up mirror. It may be easier to see if you use your hands to gently spread the inner lips apart. Try to squeeze the PC muscle and let it go loose. When you feel the muscle is relaxed, slip just the lubricated tip of the finger or tampon into your vagina. Hold it there and try squeezing the PC muscle again. You should be able to feel your vagina move a little, gently squeezing on the finger or tampon. The PC muscles only surround the outer inch or two of your vagina. The deeper part of the vagina cannot squeeze voluntarily.

Once you have found your PC muscle, you should practice squeezing and relaxing it daily. These exercises are called "Kegels" because the gynecologist who invented them was named Arnold Kegel. You can do Kegels almost any time - in the shower, while watching TV, or during lunch. Try to make Kegels a part of your daily routine, twice a day. There are several ways to do Kegels, but this method is easy to remember: Squeeze the PC muscle for a count of 3 and then let it relax as loosely as you can. Do 10 Kegels

in a row. It only takes a couple of minutes to do 10 Kegels, but practicing can help you learn to feel the difference between tension and relaxation in your PC muscle.

Some sex therapists believe that Kegels strengthen the PC muscle and help women reach orgasm (climax) more easily. There is little scientific evidence for this idea, but Kegels certainly will not hurt you! They may increase your sexual excitement by making you more aware of pleasant feelings in your vagina. Men and women sometimes enjoy the sensation of a woman squeezing her PC muscle during intercourse. Once you have been able to have full penetration without tightness or pain, you can experiment during intercourse with rhythmically squeezing your PC muscle.

### LOSS OF DESIRE

One of the most common sexual problems that women experience after ovarian cancer is loss of desire for sex. Often this change is severe, so that a woman finds herself having few sexual thoughts or fantasies, and not being frustrated if she is deprived of sex. She may crave hugging and cuddling with a partner, but be turned off by the idea of sexual touching and intercourse. Again, hormonal changes may play a role in loss of desire. The ovaries make a third group of hormones, called androgens. One of the strongest androgens is testosterone, the same hormone made in a man's testicles. In women, the much smaller amounts of testosterone that circulate in the blood are enough to stimulate sexual desire in the brain.

This system is still poorly understood. When most women go through natural menopause, their ovaries keep on making enough androgens for many years so that there is no major loss of desire. When a woman's ovaries are both surgically removed, however, her androgen levels drop suddenly, and desire problems seem to be more common. Still, even without the ovaries, women's adrenal glands, which sit on top of each kidney, produce almost half of the androgens in the bloodstream. These may be enough for some women to have normal desire for sex.

Currently there is a fad to give women androgen replacement, often in the form of a gel or skin patch. It is unclear which women truly need this treatment, or how much better it is than a sugar pill. Women who have had ovarian cancer should be just as careful about taking testosterone as they are about taking estrogen. Testosterone is transformed into estrogen in the body, and may have unknown impacts on hormone-sensitive tumor cells.

Emotional factors are very important in women's loss of sexual interest after cancer. In a study of over 200 ovarian cancer survivors, women were more interested in sex if they had fewer physical symptoms, felt more feminine, and had a higher level of education. In general, women with more education tend to report fewer problems with sex, perhaps because their greater knowledge about their bodies, or comfort with sexual communication leads to more satisfying interactions with a partner. After cancer, many women experience chronic fatigue, distress about changes in their appearance, and mild depression. All of these can interfere with feeling sexually vital and attractive. Medications that women commonly take during and after cancer treatment, especially opiate pain medications, antidepressants, anti-anxiety drugs, and anti-nausea drugs, can also diminish sexual desire.

**If your desire for sex has decreased greatly since your cancer diagnosis, here is a list of questions to ask yourself:**

1. Do you ever get turned on, for example on seeing a sexy love scene in a movie, or with a partner who usually would attract you? If not, your problem is more likely to have a medical cause.
2. Are you in a phase of treatment or recovery when you still have a lot of physical symptoms, such as pain, bloating, or fatigue? If so, acknowledge that you are working under a handicap. You may need to focus on quality rather than quantity when it comes to sex. If you plan ahead and give yourself extra time and stimulation to get in the mood, you may have a better experience.
3. Look at the medications you are taking. If you think one or more could be interfering with sexual desire (or making it very hard to reach orgasm, despite some desire and excitement), ask your doctors if you could change to a drug with fewer side effects, or whether you still need the medication at all.
4. How do you feel about your physical attractiveness? Most women are very tough on themselves in judging their appearance. If your cancer treatment has caused changes, such as weight gain, complexion changes, stomach bloating, hair loss, etc., you may be having an especially difficult time feeling good about yourself. Try taking special care of yourself. Take a bubble bath or massage or wear a favorite outfit. Focus on the things you like best about your looks, as well as on your inner beauty. Negative thoughts about yourself during lovemaking will interfere with enjoying sex if you let them. Try to fill your mind with a sex fantasy instead.
5. Look at the medications you are taking. If you think one or more could be interfering with sexual desire (or making it very hard to reach orgasm, despite some desire and excitement), ask your doctors if you could change to a drug with fewer side effects, or whether you still need the medication at all.

If nothing else works, you may want to look into testosterone replacement therapy, but be sure to ask your oncologist about safety issues.

### **Special Considerations**

If you have a colostomy there are some things that you can do so that it does not interfere with your sex life.

First you need to make sure that the pouch fits correctly. Check the seal and empty the pouch before making love. Some women have made "pretty" pouches that can cover the plastic pouch itself. Tying a pretty sash around their waist - or wearing a long shirt can also be helpful in helping you feel sexy. Some women have made themselves panties that are crotchless that serve to not only cover the appliance but also secure it. This can also be done with a teddy - some of which are already crotchless.

For women that only have to irrigate their colostomy - you may only need to use a stoma cover. If despite your best efforts to secure your pouch you still have some leakage - make it part of the experience. You and your partner can get in the shower and together clean up - making it part of the lovemaking rather than an experience that

ruins the "mood".

On days when you are likely to make love avoid gassy or spicy foods - this will reduce the amount of gas that might occur.

Some women feel sexual pleasure when their ostomy is touched - there is nothing wrong with this. You must however remember that your ostomy is very tender and easily irritated - it can even be torn with excessive rubbing. You must also never put anything into your ostomy as damage can occur from that as well.

### **OVARIAN CANCER TREATMENT AND SEXUAL PLEASURE**

It may surprise you to know that the surgery generally done for ovarian cancer rarely interferes with a woman's ability to feel sexual sensations on her vulva or in her vagina. Most women can reach orgasm after ovarian cancer with the same types of stimulation as before. The nerves that are important in a woman's sexual response do not run through the center of the pelvis, where the uterus and ovaries are removed, but rather run along the side walls, protected under a layer of tissue.

Although there have not been many studies of women's sexual pleasure after surgery for ovarian cancer, several large studies of hysterectomy show that removing the uterus does not interfere with sensation or orgasm.

What if you have noticed a loss of sensitivity and pleasure with sexual touch since your cancer? It may be linked to trouble getting in the mood for sex. If you have little desire, it is hard to get turned on.

You may also worry about disappointing your partner, producing more negative thoughts to distract you during sex! If you feel comfortable with self-touch, consider exploring your own body for pleasure. From a medical or psychological point of view, self-touch is a healthy part of a woman's sexuality.

Self-touch can be a way of exploring what kinds of caress on the vulva or breast area bring good feelings, without worrying that you are too slow to get turned on, or will disappoint your partner. If you learn about your body through self-touch, you can teach your partner how you would like to be touched. This could be helpful in recovering sexual pleasure. You could even try getting a vibrator (the wand type or handheld type with attachments work better for women than the penis-shaped ones from adult bookstores). Experiment with touching it gently near your clitoris or vaginal entrance to see what pleasure you can feel.

### **SEXUAL COMMUNICATION**

Even if you feel like you and your partner never needed to talk about sex before, it is time to communicate now. Your needs have changed because of your cancer. Your partner may also be worrying about hurting you, or pushing you into having sex when you are not interested.

**Following are some questions to think about:**

- Can your partner usually tell if you are in the mood for sex?
- How does your partner let you know they are interested in making love?



- If you want a certain type of touch or caress during sex, do you usually wait and see if your partner will do it without your asking, do you give your partner a signal physically, or do you say what you want in words?
- Have you and your partner ever discussed your sex life since your cancer?
- Since your cancer treatment, is there any kind of sexual caressing that no longer occurs during lovemaking? If so, have you and your partner talked about it?

Maybe you had good answers to all those questions, and your sexual communication does not need to improve. If you would like to be able to talk about sex more openly with your partner, here are some suggestions:

- Plan a specific talk about sex when you have privacy and time. You may need to "make a date" with your partner to talk.
- Have this talk outside the bedroom. It is often more relaxing and less tense to talk about sex before, instead of during, your actual lovemaking.
- Start by explaining why your sex life is important to you, and what you would ideally like to see happen .
- To begin, focus on one or two small changes you would like to make in your sex life . Maybe you would like to spend more time on foreplay, would like him to try oral sex more often, or would like him to help you use some extra lubricant as part of lovemaking.
- Be specific and positive in asking for change. Avoid criticizing your partner.
- If he has an erection problem, make some constructive suggestions about seeking medical help. Men are lucky in that a variety of treatments are now available for their sexual problems.

## RELATIONSHIPS AFTER OVARIAN CANCER

Although there is a myth that cancer leads to divorce, there is no evidence that divorce is more common after one partner goes through treatment. In fact, a majority of couples say that cancer brought them closer, making them value each other more. It is extremely important for couples to continue expressing love and physical affection, even during periods when an active sex life is out of reach.

It also appears more common, however, to have some specific relationship problems when the woman is the one with cancer. Men sometimes do not have as easy a time with caretaking as women do, and may even resent having to take on more household responsibilities. Many men are not as open in discussing negative emotions as women are. They may cope with a woman's fear or sadness by encouraging her to cheer up and be strong.

Women often find themselves turning to their friends, or to a support group, when they want a shoulder on which to cry . This pattern is far from universal, however. The women whose relationships are most vulnerable are those who already were having conflicts with their partners before cancer diagnosis.

Women diagnosed at a young age also may face more relationship stress because of potential infertility, higher expectations about being sexually active, and also the multiple roles of raising children , managing a household, and working outside the home.

## Dating after Cancer

Women who are not married or in a committed relationship after their ovarian cancer often feel very anxious about trying to date.

Common worries that may prevent a woman from trying to meet a new partner include:

- Fear that a new partner will be turned off by the physical changes from cancer treatment.
- Fear that a new partner will not want to deal with the possibility of cancer progressing or recurring.
- Fear of being unable to satisfy a new partner sexually.
- Fear that a new partner will not want a permanent relationship with a woman who is Infertile.

When a woman is able to meet someone new who still finds her attractive and lovable, it can be a very positive experience. To achieve that goal, however, she must risk rejection, like any woman who puts herself in the dating market. Try to think of it this way: Would you want a man in your life who could not value you because of your cancer experience? If you meet such a man, better to find out quickly, before you feel emotionally involved.

Perhaps the most common question women have about dating is when to tell a partner about the ovarian cancer. You do not have to tell someone about your cancer the first time you meet. Some people may be scared off by your bringing up something so serious, and will not make the effort to get to know you as a person if you tell them too quickly. Sometimes, however, you meet someone who seems like an old friend after one evening. Perhaps in this situation, you may want to talk about ovarian cancer.

It is best to bring up the topic before a relationship starts getting really serious. If you date someone for several months before mentioning you have had ovarian cancer, your partner may feel angry that you kept it a secret. If someone cares about you as a friend, or better yet, is in love with you, they should be able to deal with your cancer.

If you are not sure how to tell a partner about your cancer, practice with a friend before you try it for real. You may even ask your friend to pretend to give you a really negative response, and practice how you would cope. When you tell someone in real life about your cancer, chances are that it will be much easier than you expected.

## OPTIONS FOR PARENTHOOD AFTER OVARIAN CANCER

Although most women are past the age of childbearing when they are diagnosed with ovarian cancer, a number of women do get treated before the age of 45. As women postpone having babies until later ages, the number of women whose family-building is disrupted by cancer increases.

As mentioned before, younger women with germ cell tumors, borderline tumors, or very early stage, low grade epithelial tumors who are interested in future pregnancy can often keep one ovary as well as the uterus. Platinum-based chemotherapy, given for germ cell tumors often leaves a woman able to menstruate and get pregnant within a few months of stopping treatment. However, chemotherapy can cause some damage to the ovary, and can put a woman at risk for early menopause. If a young woman wants to have children, it may make sense not to wait too many years.

When both ovaries must be removed, few options for fertility remain. Although some women do a cycle of in vitro fertilization (IVF) before beginning cancer treatment, most oncologists would not advise a woman with ovarian cancer to take this chance.

The hormones that are given to stimulate multiple eggs to ripen might also lead to tumor growth. Even the procedure in which a needle is put into each follicle on the surface of the ovary to harvest a ripe egg might spread cancer cells in a woman with ovarian cancer.

If this is a concern, women would also be advised to avoid "natural cycle IVF" in which the one or two eggs that ripen at ovulation are harvested without any extra hormone stimulation.

Another recent option is to freeze some ovarian tissue before cancer treatment, in the hope that it could be transplanted back into a woman's body later on, and that it would produce hormones and ripe eggs.

Again, a special concern with ovarian cancer would be that some malignant cells (or at least cells with the potential to turn malignant) could lurk in the frozen samples and be reactivated if the tissue were put back into the woman's body.

Usually the uterus is removed along with the ovaries, also preventing a woman from being able to carry a pregnancy in the future. In this situation she would have two options to become a parent: adoption or third party reproduction. Adoption is possible for cancer survivors, although anecdotally, it may be easier to do international adoptions than to work with domestic agencies. It is very important to have a letter from the oncologist stating that you have a good chance for a normal lifespan. Some international countries are more willing than others to allow cancer survivors to adopt. Some have rules saying you must be at least a certain number of years out from your diagnosis of cancer. Unfortunately adoption has become very expensive (particularly international adoption).

Another choice is to have a baby from a donated embryo that a couple did not use in the course of their infertility treatment. An embryo can also be "custom-made" using eggs from a young woman donor and the sperm from the man in the couple.

An ovarian cancer Survivor would probably need to hire a woman (called a gestational carrier or surrogate) who would have the embryo(s) implanted in her uterus, and if the procedure was a success, would carry the pregnancy to term. Despite the publicity when one of these agreements goes wrong, hundreds of children are quietly born in this fashion every year in the United States. Again, one of the biggest barriers is the expense. If a woman has a sister, cousin, or friend who is healthy (not at increased genetic risk for ovarian cancer), and willing to either donate eggs or carry the pregnancy without being financially compensated, it may be more affordable.

**Coping with the Grief of Infertility** For some women, infertility is more painful than the life-threatening aspect of ovarian cancer. Young women diagnosed with cancer often feel an increased longing for children and believe that their experience with illness will make them more patient and loving as parents.

Feelings of grief may be the strongest for women who have never had a child, but can also be very intense for women who already have children, but had not completed their family. Sometimes a woman has children, but now has a new partner and would like to have a child with him.

**If you are coping with infertility, here are some common emotional reactions you may experience:**

- All of a sudden you notice babies and small children everywhere. There are not really more of them than before, but your mind is focused on infertility.
- You may not be able to enjoy other people's children, but instead find yourself crying or feeling angry when you see them.
- You may feel upset at family occasions or holidays, especially if other family members have small children who become the center of attention.
- You may feel misunderstood. People who care about you may say you should be grateful that your cancer is under control. They may urge you to put aside your feelings about wanting a baby.
- You may feel rage when you see a parent mistreating a child, or hear a story about an unwanted pregnancy.

It may help you to talk with another woman who is in a similar situation. You will usually feel less alone and more understood. You may be able to find other young cancer survivors by joining a local support group, or participating in online phone buddy matching or bulletin boards at sites such as [youngsurvivors.com](http://youngsurvivors.com), [fertilehope.org](http://fertilehope.org), or [esolve.org](http://esolve.org).

Give yourself permission to avoid social situations that make you feel upset, even if family and friends do not understand. You can explain that it is hard for you to be around babies right now, and that you are trying

to take care of your health by keeping your stress levels down. Consider having some counseling with a mental health professional who has experience with infertility issues. Ideally it would be helpful to find a counselor who understands cancer and infertility.

## 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.

## YOUR ROLE IN THE DECISION-MAKING 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.

For women with ovarian cancer, an excellent source of information is the book, *Ovarian Cancer: Your Guide to Taking Control* (2003) by Kristine Conner and Lauren Langford. A section of this book discusses how to find the right doctor and how to establish a good working relationship with him/her.

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?)

## SUPPORT SERVICES

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.

### 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.

### 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.

### 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.



## FIND A COMMUNITY NEAR YOU

Our communities span the country, encompassing local markets that make up our regions that are essential to the fulfillment of the NOCC mission. For survivors and their caregivers, it's a compassionate connection to ovarian cancer support groups, educational programs, events, and link to information and resources that follow them throughout their journey. For volunteers, it's the hub for donating the time and resources we need to raise funds and awareness, support survivors and caregivers, fund research and find a cure.

**To find a community near you visit:**

<https://ovarian.org/get-involved/nocc-communities/>



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