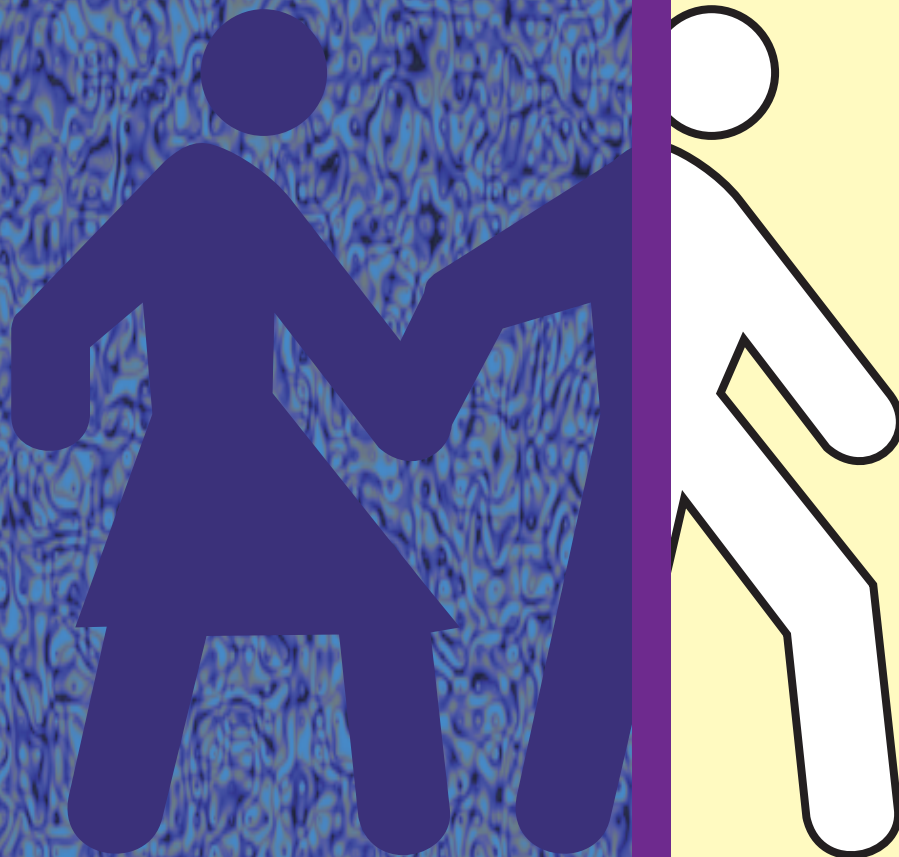




**INFORMATION GUIDE
FOR THE
MALE PARTNERS
OF WOMEN
WITH
GYNECOLOGIC
CANCER**



brought to you by
The Mount Sinai Department of Social Work Services
and
**The Mount Sinai Department of
Obstetrics, Gynecology and Reproductive Sciences**

Arden Moulton, LMSW
Edited by Ken Atkatz

**Mount
Sinai**



INFORMATION GUIDE FOR THE MALE PARTNERS OF WOMEN WITH GYNECOLOGIC CANCER

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Reliable resources and tips can be found within chapters



To Our Male Partners

The purpose of this guide is to provide you, the male partner of a woman diagnosed with gynecologic cancer, with information that will make you a more effective and supportive caregiver.

Guidance on what to include and tips on how to manage were provided by men whose partners have completed treatment. These men generously shared their experiences to help other men cope with the practical issues associated with the diagnosis and treatment of gynecologic cancer. They also provide information and tips on how to care for you during this time.

Each couple will have unique concerns and questions, but there are some topics our male advisors identified as being of special importance. Each topic is addressed in the guide and each chapter contains tips from male caregivers and a list of resources.

A diagnosis of gynecologic cancer impacts everyone in a family. It may be frightening and overwhelming, especially immediately following diagnosis. You may experience shock and disbelief during this time. But you will both gradually adjust, and many survivors of gynecologic cancer and their partners report positive changes in both their relationships and their appreciation for life. We hope the information included in this guide helps you and your partner cope during this difficult and demanding time.

Please contact us at 212 241-3793 with questions or comments, and any ideas for content. We value your opinion!

All the best,

Arden Moulton, LMSW, Woman to Woman Program Coordinator
The Mount Sinai Department of Social Work Services

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Practical Information about Mount Sinai

Important Addresses

The Mount Sinai Medical Center is located in New York City between 98th and 101st Streets, and between Fifth and Madison Avenues. The following are addresses for the Department of Gynecologic Oncology Treatment Centers:

Inpatient	Klingenstein Pavilion, 1176 Fifth Avenue, between 98th and 99th Streets, 4th Floor
The Mount Sinai Department of Gynecologic Oncology Clinic	1176 Fifth Avenue, between 98th and 99th Streets, E Level
The Rutenberg Cancer Treatment Center Gynecologic Oncology Doctors' Offices and Chemotherapy Treatment Suite	1468 Madison Avenue, between 100th and 101st Streets, First Floor
The Rutenberg Cancer Treatment Center Department of Radiation Oncology	1468 Madison Avenue, between 100th and 101st Streets, MC Level
Parking	99th Street, between Madison and Park Avenues

Important Numbers

Mount Sinai Hospital	212 241-6500
Klingenstein Pavilion 4th Floor Reception	212 241-5513
Rutenberg Treatment Center	212 241-8453
Radiation Oncology	212 241-6158
Gynecologic Oncology Clinic	212 241-6716
Social Work	<i>Alison David</i> 212 241-5189 <i>Arden Moulton,</i> <i>Woman to Woman Program</i> <i>Coordinator</i> 212 241-3793
Private Duty Nurses at Mount Sinai	212 241-7383
Mount Sinai Business Office	212 731-3100
Mount Sinai Patient Representative Office	212 241-6848



About the Healthcare Professionals of Mount Sinai

Doctors

Your partner's medical team includes her *attending*, a doctor who is fully licensed and trained to provide treatment for gynecologic cancer and a team of student physicians who will manage her care during treatment. This team includes two *residents* rotating through the Department of Gynecologic Oncology, managed by a *fellow*, receiving three years of post-residency training in gynecologic oncology. While your partner is hospitalized, you will see the fellow and the residents twice a day during rounds. This is the time to ask questions and resolve problems.

Registered Nurses

Nurses are licensed and trained to provide patient care and dispense medications. One or more members of the nursing staff are available to every hospitalized patient 24 hours a day.

Patient Care Associates

These hospital staffers are available to help patients with meals, hygiene, personal grooming, cleaning, and other concerns of daily living.

Social Workers

Licensed and trained to provide emotional support, practical guidance, and discharge planning, social workers are your advocates within the hospital and your link to resources in the community (such as government programs, legal services, and charitable organizations). A social worker will meet with you a few days after surgery and at any time thereafter, as needed.

In the Neighborhood

The following list does not constitute a recommendation of any particular restaurant or drug store – only those closest to Mount Sinai Hospital:

Restaurants

Hanratty's, 1410 Madison, between 97th and 98th Streets, 212 369-3488
Peter's Coffee Shop, 1413 Madison at 98th Street, 212 722-4400
3 Guys, 49 East 96th Street, at Madison Avenue, 212 348-3800

Drug Stores

Madison Avenue Pharmacy, 1407 Madison Avenue, between 97th and 98th Streets, 212 722-3200, Drug Loft, 1412 Madison Avenue @ 98th Street, 212 996-9499, Duane Reade, 1490 Madison Avenue @ 102nd Street, 212 996-9246

Transportation

Transportation to and from Mount Sinai includes public transportation on wheelchair-accessible buses, travel by private or hired car and, for eligible patients, Access-a-Ride van service. Access-a-Ride is available to patients unable to use public transportation, provides door-to-door service, and costs \$2 for a one-way trip. Information about Access-a-Ride is available through the New York City Transit Department at 646 252-5252.

If your partner receives Medicaid and is medically eligible, she may be entitled to transportation services including MetroCards, shared van service, and ambulances if necessary.

If none of these options are accessible or affordable, call CancerCare at 800 813-4673 or the American Cancer Society at 800 227-2345. If you are financially eligible, they may provide funds to help with transportation.

Speak to the gynecologic oncology social worker for more information on eligibility and availability.



Housing

Mount Sinai Guest Residence, 3 East 101st Street, provides housing for patients and their families, 212 838-3200

Hotel Wales, 1295 Madison Avenue, between 92nd and 93rd Streets, offers special rates for Mount Sinai patients, 212 876-6000

For other possibilities, visit the website www.joesplace.org, which provides housing information for people diagnosed with cancer and their families.



What You Can Do to Help

You will probably have two new jobs during your partner's treatment, that of CAREGIVER and that of ADVOCATE. But it's important before you take on any role to ask your partner how you can be helpful; most women patients find it reassuring to maintain as much of their regular schedule as possible, and may prefer to handle certain tasks for themselves. As a survivor of ovarian cancer told us, "I am the same person I was before I got cancer."

Your work as CAREGIVER may involve the following:

1. Helping to maintain the household — including cooking (or arranging for food from friends or take-out sources), cleaning, childcare, driving, and any other task for which your partner requests help.
2. Keeping track of your partner's medical appointments and treatment schedule. You should get a calendar especially for this purpose.
3. Keeping a list of all medications, including over-the-counter medications, for both of you to carry with you at all times.
4. Providing reassurance of your continued love. This includes being affectionate and patient (treatment for cancer is an emotional roller coaster ride), listening attentively when your partner wants to talk (and not pressuring her to talk if she doesn't want to), and assuring her that you will take an active role in her recovery. You are in this fight together.
5. Encouraging your partner to move forward, one day at a time. Some women question why they got cancer. Cancer is caused by a variety of factors, most still not understood, and it is non-productive for her to feel guilty about what she did or did not do to get cancer.
6. Hope and optimism are important to your quality of life during treatment, but there is no correlation between optimism and survival. A cancer journey has many ups and lots of downs. Cancer is an anxiety-filled experience. You can't always avoid the negative emotions, but you can strive for honesty about how you're feeling and accept that the ups and downs are normal.

Your job as ADVOCATE includes the following:

1. Advocating for your partner with doctors, nurses, and the hospital bureaucracy. Ask healthcare professionals to limit their use of medical jargon, to give you enough time to discuss your concerns and ask your questions, and to explain things to you so they are perfectly clear. The new world you have found yourself a part of speaks a language you may not understand. Do not leave the hospital or doctor's office until you understand everything that has been said. And don't be afraid to question a treatment choice. You and your partner should be absolutely convinced that she is receiving the best possible care. It is very important that you and your partner feel comfortable with her doctor. You should feel supported, unrushed and comfortable. Think about

Second Opinions

Most doctors are comfortable with their patients' seeking a second opinion. Getting another opinion will help reassure you that your partner is receiving the best treatment.

We advise you to get a second opinion from a gynecologic oncologist at a hospital that treats a large number of women. Before you meet the doctor, ask how many cases of ovarian cancer (for example) he or she has treated. To find a high-volume treatment center, access one of the following:

National Cancer Institute. A list of centers can be found on their website: <http://cancercenters.cancer.gov>, or call 800-4-CANCER.

The American College of Surgeons. This organization, which is dedicated to safeguarding standards of care, evaluates cancer treatment programs and lists approved centers on its website: www.facs.org/cancerprogram/howto.html

Groups that advocate for certain cancers are also a good source of information. For example, you can call the Ovarian Cancer National Alliance at 202 331-1332 for information about centers that treat large numbers of women diagnosed with ovarian cancer.

Before your partner's appointment, check with your insurance provider to be sure they will cover the cost of a second opinion.



getting a second opinion. It is a good way to feel confident about your partner's care.

2. Act as a go-between with family and friends. Be your partner's advocate by screening calls and visits. Tell friends and family what is helpful and what is not (for example, calling after 10 at night is not helpful).
3. Make a list of questions before doctors' appointments and be sure one of you writes down the answers.
4. You and your partner will likely access the Internet for information. While there are many useful sites, there is also a great deal of inaccurate and out-of-date information that may both misinform and frighten you. Be cautious when you visit a website—be sure the source is reliable. We have included a list of reputable websites, but remember that they contain only general information and should not be used as a substitute for advice on your partner's specific condition from her own doctor.

TIPS FROM MEN

“My wife's doctor urged us to stay off the internet completely. He said information changes constantly and some of the information on the internet is either conflicting or inaccurate. Your wife is a unique individual not a statistic.”

“Help your partner manage her medications. Buy a pillbox labeled with the days of the week and help her keep track by making a list of medications and when she is scheduled to take them. Take the list with you for all doctors' appointments.”

WHAT WOMEN SAY

“More than anything, I just want you to listen, really listen. I do not expect you to fix my cancer, but I need to vent. Don't talk, just please listen.”

“One of the worst things is feeling a loss of control. Please allow me control over other things, like decisions about treatment, how to tell people, what to eat, how much to exercise.”

Websites

Cancer Care provides free support, financial information and practical help: www.cancercare.org.

National Cancer Institute offers information on gynecologic cancers and a dictionary of terms, with links to both on its opening page: www.cancer.gov.

Gynecologic Cancer Foundation is a not-for-profit organization established by the Society of Gynecologic Oncologists. It offers helpful, easy-to-understand information about gynecologic cancer: www.thegcf.org.

The Ovarian Cancer Research Fund is a nonprofit organization that funds research projects on ovarian cancer. Information about current projects is available at www.ocrf.org.

Pamphlet

“How to Find Medical Information” details ways to use the Internet wisely. Go to the Federal Citizen Information Center (www.pueblo.gsa.gov) and click on “Health.”

A Very Helpful Book

Gruman, Jessie, PhD. *After Shock: What to Do When the Doctor Gives You — or Someone You Love — a Devastating Diagnosis*. Walker & Company, 2007.



What Is Gynecologic Cancer and How Is It Treated?

Gynecologic cancer occurs when cells in a part of a woman's reproductive system grow and divide abnormally. Cells are the building blocks of the tissues that make up the organs of the body. Normal cells divide only to replace worn-out or dying cells. Cancer cells, instead of dying, outlive normal cells, grow abnormally, and form a growth, or mass of tissue, called a malignant tumor, which can then spread its cancer cells throughout the body. A malignant tumor that starts in a woman's ovaries is called ovarian cancer and one that starts in the uterus is called uterine cancer.

Doctors do not know what causes most reproductive cancers but they have identified certain risk factors. Risk factors may increase a woman's chance of getting gynecologic cancer, but they do not make it inevitable. Only a small percentage of women with risk factors for a particular cancer (for example, a close relative with that cancer) will develop the disease.

Treatments

Treatment for gynecologic cancer is individualized for each woman, depending upon the type and stage of the cancer, her overall health, and whether or not she wants to have children. The stages, numbered from 1 to 4, indicate how far the cancer has spread. Because treatments vary according to stage, staging is necessary, and is done after doctors have gathered all the information from diagnostic tests. Stage 1 means the cancer has not spread beyond the reproductive organ involved. Stage 4 indicates that the cancer has spread to distant areas.

After diagnostic tests are completed, a doctor will recommend one or more treatment choices. The main choices of treatment for the three most common gynecologic cancers — uterine, cervical, and ovarian — are *surgery*, *chemotherapy*, and *radiation*. Some women will be advised to have one kind of treatment; other women may receive a combination of two or all three. Whatever treatment options are recommended for your partner, take the time to understand the purpose of each treatment and the possible side effects associated with it. This is another good time for a second opinion; you both want to be confident that the recommended treatment is appropriate (see box "Second Opinions" on page 5).

Surgery

The main treatment for ovarian, uterine and some cervical cancers is surgery. The gynecologic oncologist may perform an operation called radical hysterectomy with bilateral salpingo-oophorectomy. This is the medical terminology for removal of the uterus, ovaries, fallopian tubes, and cervix. To perform this operation, the surgeon will make an incision in the patient's abdomen. Lymph nodes near the tumor will also be removed and examined to determine if the cancer has spread beyond the ovary or uterus. Sometimes cervical cancer surgery involves removal of just the uterus (which includes the cervix). This is called a total or simple hysterectomy. The vagina stays intact and lymph nodes in the pelvis are usually not removed. The ovaries and fallopian tubes are usually left in place.

Clinical Trials

A clinical trial is a study of an experimental treatment. Clinical trials are a possibility when your partner's doctor determines that the treatment being studied may be helpful. Taking part in a clinical trial is a decision you and your partner should make in consultation with her doctor. Here are some ideas that can help with the decision:

First, you should know that there are three phases in clinical trials. Phase-one trials study the most effective and safest way to give a new treatment. Phase-two trials determine the effectiveness of a new treatment. Phase-three trials involve large numbers of women divided into two groups: one that receives the treatment and one that receives standard treatment.

Ask your partner's doctor the purpose of the study and what the treatment does. Ask also about side effects, long-term follow-up, and support by the healthcare team during the trial.

Mount Sinai Hospital is a designated Gynecologic Oncology Group clinical trial center. Ask your partner's doctor if a clinical trial may be appropriate for her.



Your partner will be hospitalized for 1-7 days depending on the type of surgery. It will take from 4-6 weeks for complete recovery, also dependent upon the type of surgery. Complications are rare, and any possible complications will be explained by the medical team.

Chemotherapy

Chemotherapy drugs kill cancer cells to keep them from growing or multiplying. After a tumor is removed surgically, chemotherapy is used to remove any cells that may have spread beyond the reproductive organs. This is called adjuvant or helping chemotherapy. Sometimes chemotherapy is used prior to surgery to shrink the tumor.

Chemotherapy drugs are given through a vein or the abdomen. The drugs enter the bloodstream and circulate to all parts of the body. Because healthy cells in the body are also affected — including those in the digestive tract, bone marrow, and hair follicles — side effects including nausea, fatigue, and loss of hair may occur (see “Possible Side Effects of Treatment” on page 9).

Your partner will probably be fearful of chemotherapy and its widely discussed side effects. Your partner’s doctor should explain the possible side effects of her particular chemotherapy regime and reassure her that every woman’s response to chemotherapy is different. Many women continue to work, exercise, and live their lives normally while on chemotherapy.

Radiation

There are two kinds of radiation therapy, *external beam* using high-energy radiation to target a specific area, and *brachytherapy* using radioactive materials placed near the tumor. Both kinds of radiation are used to treat some uterine and cervical cancers following surgery. These treatments shrink tumors and eliminate cancer cells. Radiation therapy usually begins 4-6 week after surgery. External beam radiation usually requires 4-5 weeks of treatment 5 days a week. Each treatment takes about ½ hour.

Complementary Treatments

These are therapies that include massage, acupuncture, nutritional guidance, meditation, aromatherapy, and those vitamins and supplements which careful research has shown to be safe. These interventions often reduce stress and may help alleviate some treatment side effects. However, they do not cure cancer, and you should discuss the use of complementary treatments with your partner’s doctor. Alternative treatments for the disease itself that fall outside proven, research-based therapies are not an option for women with gynecologic cancer. There are currently no viable alternatives to standard treatment for gynecologic cancer.

TIP FROM A MALE PARTNER

“I think complementary treatments — especially meditation and good nutrition — made my wife stronger mentally and physically.”

Information on Clinical Trials

The American Cancer Society provides a clinical trials matching service for patients through the ACS cancer information center: 800 227-2345.

The National Cancer Institute provides general information about treatment for gynecologic cancer and information about clinical trials. Click on links on the opening page: www.cancer.gov.

The National Comprehensive Cancer Network is a consortium of 20 top cancer centers. It offers current information about treatment: www.nccn.org.

The Gynecologic Oncology Group is a national organization that focuses on clinical trials specifically for gynecologic cancer. The website is designed for research investigators but lists the names and numbers of institutions taking part in GOG clinical trials: www.gog.org.

Resources on Complementary Treatments

The National Center for Complementary and Alternative Medicine is a federally funded center that supports research on complementary treatments. Their website CAM on PubMed allows you to search for materials on complementary medicine in the National Library of medicine database: <http://nccam.nih.gov/camonpubmed>.

MD Anderson Cancer Center Complementary/Integrative Medicine provides patients with educational materials on complementary medicines to help integrate them with traditional treatment: www.mdanderson.org/departments/ci-mer.



Possible Side Effects of Treatment

Nearly all medical treatments sometimes cause side effects — changes in the body that are not desired by the doctor or the patient. Some side effects are simply uncomfortable; others can be more severe. Not every patient has the same side effects or has them to the same degree, and there are many ways to limit and control the discomfort associated with them. The doctor can also prescribe one of the effective new drugs now available to reduce some of the side effects discussed here.

Side Effects of Surgery

As with any serious abdominal operation, patients are typically tired and in pain following surgery for gynecologic cancer. The doctor may prescribe pain medications, and the body's natural healing powers should reduce the side effects over time.

How You Can Help

1. Talk to your partner about visitors. Most women are uncomfortable following surgery, and it can be difficult to receive visitors.
2. Before you leave the hospital, make sure you have all necessary prescriptions and a phone number to call if your partner has questions or concerns.
3. When your partner returns home, monitor her pain medications and don't let her lift anything heavy for a while — this is one of the exceptions to the rule about asking her how much she wants to do.
4. During the weeks following surgery your partner will need your physical and emotional support. The physical support you can provide includes helping with meals, driving, childcare, and other household tasks. On the emotional side, being a supportive, reassuring presence can help in many ways. Assure your partner that you will be there for her. Her emotions may include anxiety, fear, and feeling out of control and overwhelmed. Being a good listener is especially helpful at this time, because many women adjust to the stress of surgery by telling and retelling the story of their experiences.
5. Most women do not need nursing help at home following surgery, and insurance will only pay for nurses if doctors believe it is a "medical necessity." Speak to the gynecologic oncology social worker if you have concerns or questions, or think your partner will need a nurse or special equipment at home.

TIPS FROM MEN

"We realized after we got home to New Jersey that a mistake had been made on one of my wife's prescriptions. Double check everything with the medical staff before leaving the hospital."

"The best gift we received when we got home from the hospital was food. Not having to worry about cooking was a huge help."



ADDITIONAL TIPS FROM MEN

“The first week after she got home from the hospital, my wife wanted no visitors outside the family. She was tired and not ready to see anyone.”

“The best way to respond is to say: ‘I understand how you are feeling. Is there anything I can do to make you feel better? Or do you just want to talk about it?’” — Marc Silver, in *Breast Cancer Husband* (Rodale Books, 2004)

Side Effects of Chemotherapy

Your partner will probably experience some side effects following her chemotherapy treatments. However, since the drugs used and the interval between treatments vary with each patient (and individual tolerance to chemotherapy varies from woman to woman) the side effects may be less difficult to deal with than you expect. The ones our male advisors have told us were the most difficult for their partners were fatigue and loss of hair.

How You Can Help

1. Find out exactly which chemotherapy drugs your partner is receiving, and learn about all the possible side effects of those drugs (see box “Websites” on this page and page 6). The Mount Sinai Hospital will provide education about your partner’s specific chemotherapy drugs before her first treatment. Be sure to ask for the name and phone number of the nurse who can provide answers to any follow-up questions. Your partner may never experience severe side effects, but it is reassuring at 11:00 at night for her to know that something she is feeling is not a new symptom, but a side effect of treatment.
2. Most women receiving chemotherapy for gynecologic cancer lose their hair, starting 2-3 weeks after the first chemotherapy treatment. This is often the single most difficult part of treatment for women. Hair defines us as individuals, and being bald announces to the world that one is in treatment for cancer. Encourage your partner to go to her hairdresser and get a very short haircut. Then, when her hair starts to fall out it will not be as upsetting. Get a list of wig dealers from the hospital social worker or friends and accompany your partner to get a wig. Reassure her that she is beautiful with or without hair — and reassure her that her hair WILL grow back.
3. Get directions to the treatment center or infusion center before your partner’s first treatment. Some couples ask to tour the facility before treatment begins so they know what to expect. Get all prescriptions filled. Ask your partner’s doctor about the length of treatment and the details on how the chemotherapy is administered. The more you know, the less anxious you will be. Prepare a “comfort bag” including snacks, books or magazines, a sweater, and water.

Websites

Chemocare.com is a comprehensive resource on chemotherapy drugs, side effects, nutrition and living well during treatment: www.chemocare.com.

Medline Plus Drug Information lets you look up any drug and find information about how it works, its side effects and what medicines should not be used at the same time:

www.nlm.nih.gov/medlineplus/druginformation.html.

Books

Eyre, Harmon J., MD, *Informed Decisions: The Complete Book of Cancer Diagnosis, Treatment and Recovery*. American Cancer Society, 2002.

Judith McKay, RN, and Nancee Hirano, RN, MS, AOCN, *The Chemotherapy and Radiation Therapy Survival Guide: Information, Suggestions, and Support to Get You Through Treatment*. New Harbinger Publications, 1998.



4. Arrange for transportation to and from the treatment center. Your partner is likely to be tired following treatment and unable to safely drive herself home. Be sensitive to her emotional needs: Some women like to be alone during treatment to read and sleep; others like company.

Side Effects of Radiation

Fatigue, which may not start for a few weeks after therapy begins, is a common side effect of radiation. Your partner may also experience skin irritation causing redness. Another common side effect is diarrhea, which can be relieved by over-the-counter anti-diarrhea medication. Your partner may experience bladder irritation, which causes discomfort and the urge to urinate frequently. Vaginal stenosis, or the narrowing of the vagina caused by scar tissue, is another possible side effect of radiation. It can make intercourse painful.

How You Can Help

1. If your partner begins to experience fatigue, allow her extra time to rest, and be prepared to help with daily tasks.
2. Remind your partner to clean and protect the skin exposed to radiation. This helps control skin irritation and redness.
3. Discuss with her the possibility of using a vaginal dilator, which stretches the walls of the vagina to avoid permanent vaginal scarring.
4. Ask your partner's doctor or the oncology radiation nurses for additional suggestions on how to manage the side effects of radiation.

TIPS FROM MEN

"My wife was tired and sore following radiation. We took short walks every night, which helped with the tiredness, and her doctor told her not to use very hot water on her skin."

"You are going to participate in your partner's treatment. This will expose you to things that will be distressing. You need to be prepared to help her deal with possible side effects."

"We got very helpful and practical tips on what to do for side effects from women survivors from *Woman to Woman*.^{*} My wife listened to them because they had experienced it themselves."

"Prepare a comfortable place in the house/apartment for your partner following treatment: a favorite chair, a comforter, soothing music."

"If you live outside NYC and are traveling by car following treatment, be prepared to stop often for bathroom breaks. Chemotherapy treatment requires that your partner receive a lot of fluids."

^{}Woman to Woman is a peer to peer support program that links each patient with a gynecologic cancer survivor volunteer. Your partner will have a chance to meet a Woman to Woman volunteer before treatment begins.*



ADDITIONAL TIPS FROM MEN

“Carefully monitor your wife’s health during treatment. Make sure she is eating, and speak up if you think she is not taking care of herself. My wife experienced a side effect of chemotherapy called ‘chemobrain,’ which can cause forgetfulness.”

(Note: Chemobrain is a side effect of chemotherapy that may cause forgetfulness, lack of focus, and problems finding words. Many women report fewer symptoms a few months after the end of treatment, but chemobrain can continue for years after the completion of chemotherapy. For information about chemobrain, visit CancerCare at www.cancercare.org and click on “publications/fact sheets” for the “Chemobrain Information Series.”)

TIPS FROM WOMEN

“I need reassurance that you still love me in spite of the bald, tired stranger I have become.”



Family and Friends

Family members and friends can be an important source of support in many ways, both emotional and practical. You and your partner should discuss what kind of support would be most helpful, and which of your friends and relatives might be willing to provide it. Self-reliance can be a good thing, but receiving a cancer diagnosis is the kind of personal crisis where it makes sense to ask for assistance.

How You Can Help

1. Tell your family and friends as soon as possible. Waiting delays the comfort and support your family and friends will want to give — to both of you. And those who want to help will need guidance about what kind of support you need.
2. Decide which jobs you need help with. Ask family and friends about availability. Make a list and give everyone who offers help a specific task. Some examples of jobs you may need done include preparing meals, accompanying your partner to treatment, caring for children, and reading to your partner following treatment.
3. Keep a calendar with daily reminders of each day's activities and who is coming to help.

How to Tell the Children

How and what to tell children about your partner's cancer depends upon the age of the child. You are the experts on the subject of your children, their emotional temperaments and level of understanding. Be honest, but use language they will understand and reassure them that they are not responsible for their mother's cancer. Tell them that while their routines will change for a while, you both will be there to answer their questions and provide them with attention and love.

TIPS FROM MEN

“Before you tell people every detail, know your audience. Understand that your wife's elderly mother might not be able to handle everything.”

“Give your kids more responsibilities around the house. It is helpful to the family and makes them feel they are helping their mother.”

How to Keep Everyone in Touch

If you and your partner want to keep friends and family informed and up-to-date with a minimum of back-and-forth calling, let technology help:

- Record a message on your answering machine that says: “We appreciate your call and your concern, but please understand if we don't call you back right away. Thanks.”
- Designate one person, a sister-in-law for example, to call everyone at the end of the day with updates.
- Set up an email group of concerned family and friends. Send one email on a regular basis to the entire group.
- Use Internet sites: www.lotsahelpinghands.com or www.caring.org let you post updates of your partner's progress. Family and friends can then access the information at any time.

Websites

Cancer Care (www.cancercare.org) has a useful information sheet called “Helping Children Understand Cancer: How to Talk to Your Children about Your Cancer Diagnosis.”

Kids Connected

(www.kidskonnected.org) provides friendship and support to children who have a parent with cancer.

Books

Harpham, Wendy, MD, *When a Parent Has Cancer: A Guide to Caring for Your Children*. Harper Collins, 1997.

Ackerman, Abigail and Adrienne, *Our Mom Has Cancer*, American Cancer Society, 2001.

McCue, Kathleen, *How to Help Children Through a Parent's Serious Illness*, St. Martin's Press, 1994.



What about Our Sex Life?

Your sex life will likely be impacted by your partner's diagnosis. A diagnosis of gynecologic cancer profoundly affects a woman physically and emotionally. Recovery from surgery can take up to six weeks and the fatigue and side effects from pain medication impact sexual desire and functioning. Self-consciousness about body changes and fear that sexual intercourse may cause pain also impact a woman's adjustment. If your partner had not experienced menopause before her surgery, symptoms such as hot flashes, mood swings and vaginal dryness may occur.

Chemotherapy and radiation treatment side effects may also impact your sex life. Scarring from radiation can cause the vagina to shorten, causing discomfort for your partner, and chemotherapy side effects like nausea, hair loss, and fatigue may cause loss of desire.

How You Can Help

1. Understanding the emotional and physical effects of treatment will help you find solutions.
2. Communication is critical. Share your concerns and fears. Tell your partner you find her desirable but are willing to wait until she is ready to resume sexual activity.
3. BE PATIENT. Most of the effects of treatment for gynecologic cancer lessen when treatment ends. At that time your partner will feel better physically and emotionally. Keep in mind that every woman recovers at her own pace and some women continue to experience lack of desire. This is normal.
4. If your partner experienced orgasm before her diagnosis she will again. Some women report their orgasms feel somewhat different but they do occur.
5. If you and your partner were experiencing problems in your sex life before her diagnosis, this may be a good time to seek professional help. Talk to her doctor or the hospital social worker for a referral.
6. The use of vaginal lubricants and moisturizers can help remedy vaginal dryness.
7. Regular vaginal intercourse, if and when your partner is ready, helps stretch the vagina following radiation. If you are not ready for vaginal intercourse, vaginal dilators have the same effect. You will not feel a difference during intercourse following your partner's hysterectomy.

TIPS FROM MEN

"Be patient. Your sex life will change, temporarily, maybe forever. But with creativity and patience it will still be enjoyable."

"I experienced impotency during my wife's treatment. My wife blamed herself, telling me she was not attractive anymore. I reassured her that it was not her fault."

TIP FROM A WOMAN

"Please be patient. I love you but it's the last thing on my mind right now is sex."

Resources

"Sexuality and Cancer," American Cancer Society (1-800- 227-2345). An accurate and comprehensive guide to sexuality and cancer.

"Renewing Intimacy and Sexuality after Gynecologic Cancer," Gynecologic Cancer Foundation (www.thegcf.org). A brochure written especially for survivors of gynecologic cancer.



Financial and Legal Issues

Any serious illness creates problems that go beyond the direct issues of medical care — and gynecologic cancer is no exception. There are medical bills to pay, insurance companies to deal with, legal documents to be filled out, employers to negotiate with, and for some patients, legal rights to be called upon and government assistance to apply for. As the partner of a patient, you will probably want to help with these problems. Mount Sinai social workers and other trained staffers can assist you, or if needed, refer you to outside experts: lawyers, financial and insurance consultants, government agencies, and charitable organizations.

There are a number of financial issues that you, as caregiver, will likely have responsibility for during your partner's recovery, such as health insurance, the medical bills not covered by insurance, and out-of-pocket expenses.

Health Insurance and Medical Bills

If you and your partner have private insurance or are insured by your employers, it is important to review the policies to determine exactly what is covered by your plan. If your partner is not insured, investigate group policies through professional organizations for retired persons, teachers, or any group that either of you belongs to. Determine if your partner is eligible for Medicare (see below for resources to determine eligibility). If your partner is uninsured, the Mount Sinai Hospital will determine her eligibility for Medicaid, the state benefit program for the unemployed or those in a low income bracket.

How You Can Help

1. Do not let your partner's health insurance lapse; be sure premiums are paid on time.
2. Call your partner's insurance company to find out if a certain procedure or test needs pre-approval to avoid unexpected fees. Be sure you know the amount of your insurance co-pay.
3. Ask your partner's insurance company to assign a specific case manager to act as a link between the healthcare system and the insurance company. This will help you manage the bills.
4. If the insurance company refuses to cover a treatment or procedure, help your partner file a grievance. Ask your provider why the claim was denied and then re-submit the bill with a copy of the denial letter. If you have exhausted all options, try contacting the Consumer Services Bureau at the New York State Insurance Department Agency, Empire State Plaza, Albany, NY 12257 or www.ins.state.ny.us.

Medical Bills Not Covered by Insurance and Out-of-Pocket Expenses

There will be costs for treatment not covered by insurance, as well as out-of-pocket expenses (childcare, travel expenses, medical equipment, meals, etc.) that may present a financial burden. Fortunately, there are many ways to lighten that burden.

Resources

REAP (Resource, Entitlement and Advocacy Program) is a Mount Sinai program that gives you information about entitlement programs that may help you pay some of your bills. These entitlement programs include Medicare, Medicare Part D, Medicaid, Social Security Disability, Supplemental Security Income (SSI), Social Security Retirement, and Family Health Plus. Call 212 241-2800 for an appointment with a REAP entitlement coordinator.

Consumer Credit Counseling Service helps people learn to manage their resources, balance their budgets and get out of debt, but be aware there is a fee for their services: www.cccservices.com or call 800 355-2227.



How You Can Help

1. Ask the hospital social worker for a list of resources to help with expenses. For example, some churches have funds to support members.
2. Some out-of-pocket expenses are tax deductible. Save receipts from ALL bills and ask an expert at tax time which ones are tax deductible.
3. This is the time to reach out to family and friends for help. They will likely be grateful to provide support. If they are unable to provide direct financial support, ask them for help with things like organizing your bills or calling creditors.
4. Rank your bills in order of importance. For example, medical bills, rent or mortgage payments, utilities, and taxes should take priority.
5. If you anticipate financial problems, work out a payment plan with creditors as soon as possible. Consumer counseling organizations will help you create a plan for paying creditors.
6. Make an appointment with a financial counselor in the Mount Sinai business office to discuss problems paying medical expenses: 212 731-3100.
7. You can also call the Patient Representative Office at 212 241-6848 for support and advocacy.

TIPS FROM MEN

“Find out as soon as possible what your insurance covers and what it doesn’t. Remember that insurance companies are businesses — they will reimburse as little as possible. Find a health advocate if insurance issues overwhelm you.”

“Keep good records of medical payments and insurance reimbursements to insure that insurance thresholds are adhered to and records are available for income tax deductions. I use an accordion file carefully labeled for easy access.”

Legal Issues

You may find yourself helping to organize your partner’s legal concerns during her treatment. These may include making or changing a will and/or thinking about advance directives. Advance directives, a living will, and a healthcare proxy (also known as a durable power of attorney), allow patients to determine what kind of medical interventions (hydration, feeding, etc.) they will get if they are not able to communicate their wishes or make decisions.

Most doctors encourage women to work as much as possible during treatment. It may be financially necessary. Also, work may be a welcome distraction, and a way for your partner to return to a comforting, predictable routine. However, if your partner doctor advises her not to return to work, she and you should consider accessing the following programs:

Websites

AARP offers information for women over 50 on health insurance options: www.aarp.org/health/insurance or call 800 523-5800.

CancerCare provides referrals to financial assistance programs. Go to the “Cancer Care Services” and the “Helping Hand Guide” on their website: www.cancercares.org.

Health Insurance Information, Counseling, and Assistance Program, sponsored by the New York State Office for the Aging, provides free confidential health insurance information and assistance with Medicare, Medicaid, HMOs, Medigap insurance, medical bills and long-term health insurance: www.hiicap.state.ny.us or call 800-333-4114.

NeedyMeds offers information about programs that help patients who are financially unable to afford their medications: www.needy meds.com/indices/needymedspage.tml or call 215 625-9609.

Patient Advocate Foundation is a non-profit agency that acts as a link between patients and their insurers: www.patientadvocate.org/resources.php or 800 532-5274.

Books

Landay, David S. *Be Prepared: The Complete Financial, Legal, and Practical Guide for Living with a Life-Challenging Condition*. St. Martin’s Press, 2000.

Orin, Rhonda. *Making Them Pay: How to Get the Most from Health Insurance and Managed Care*. St. Martin’s Press, 2001.



Family Medical Leave Act (FMLA)

This federal law provides some job protections for persons who must take time off for medical reasons and for their spouse who is caring for them. The law applies to employees of an employer with fifty or more employees working in the same geographic area. To be protected, your partner must have been working for the employer for at least twelve months and have worked at least 1,250 hours during that year. This law does not provide salary replacement. It does provide job and benefit protection. When you return to work you must be allowed to return to your job or one that is equivalent. You will receive job protection for twelve weeks per year, but the weeks do not have to be taken consecutively. You may work in between weeks off – making the FMLA a good choice for women in chemotherapy treatment for gynecologic cancer.

Short Term Disability (STD)

Short term disability is private insurance that replaces a percentage of income if illness prevents your partner from working. Most companies in New York State provide the same core benefit: a seven day wait period, 50% of gross weekly income, a maximum weekly benefit of \$170 and a maximum benefit period of 26 weeks. Most employers' process short term disability claims internally. You and your partner will not be responsible for extensive paperwork to complete a claim. All employers require a doctor's statement to approve STD. Speak to your partner's employer about applying for short term disability and ask the Mount Sinai Division of Gynecologic Oncology social worker for help getting her doctor's written approval.

Long Term Disability

Social Security pays long term disability benefits to people who cannot work due to a medical condition that is expected to last at least one year or result in death. Social Security Disability is funded with Social Security taxes paid by workers. Benefits are based on an individual's age at the time they became disabled and on the amount of time they worked under social security. To be eligible for long term disability your partner, at age 60, must have worked for 9 ½ years. Your partner should apply for disability as soon as she, her doctor, and Social Security have determined her eligibility. It may take up to five months for a claim to be processed. She may apply at www.socialsecurity.gov or call 1-800-772-1213 to make an appointment to file a claim at her local Social Security office.

TIPS

Speak to your employers as soon as possible about taking a family leave of absence. Encourage your partner to apply for disability benefits as soon as possible, because the application process is lengthy. One can apply for disability online at www.ssa.gov or by phone at 800 772-1231. This office will also provide information about Medicare benefits.



How You Can Help

1. It may be difficult to discuss end of life issues, but it is important to know your partner's wishes.
2. If your partner appoints you her healthcare proxy, ask her exactly what her wishes are so you can be sure they are followed.
3. Make copies of the advance directive, keep one for yourself, and give copies to other family members and healthcare providers.



Taking Care of Yourself

The male caregivers of women with gynecologic cancer are often overlooked by healthcare providers, family, and friends. Caring for an ill partner is stressful and difficult. Both you and your partner need support, encouragement and attention to physical and emotional well being.

What You Can Do For Yourself

1. Make caring for yourself a priority. Keep doctors' appointments, rest, try not to skip meals or overeat. Exercise helps relieve stress and will help you sleep; even a quick walk will help.
2. Feeling angry or resentful is normal. Discuss your feelings with someone you trust, and don't feel guilty. It is exhausting, physically and emotionally, to care for a partner in treatment for gynecologic cancer.
3. Schedule time for the hobbies and leisure activities you enjoy. You will be a better caregiver if you take time for yourself. Ask friends to fill in for you at home.
4. Plan a vacation with your partner. It helps to have something to look forward to during or after treatment.
5. Talk to friends who have been caregivers. It helps to share feelings and get advice from someone who has lived through what you are experiencing.

Organizations and Websites

Family Care Research Program is a Michigan State University Program with a focus on family caregiving and caregiver stress:

www.healthteam.msu.edu/fcrp.

Family Caregiver Alliance is an information clearinghouse for caregivers: www.caregiver.org.

National Family Caregivers Association offers support and resources for those caring for the seriously ill: www.nfcacares.org.

Well Spouse Association is a support organization for partners of the chronically ill: www.wellspouse.org.

Book

Houts, Peter S., and Bucher, Julia A. *Caregiving: A Step by Step Resource for Caring for the Person with Cancer at Home*. The American Cancer Society, 2000.

TIPS FROM MEN

“Some advice for those who think they can do it alone. You probably can, but will likely not be as effective for yourself, your wife/partner, your kids and co-workers unless you talk to those you trust about what you are going through. You may need to seek help. Think of getting help from a therapist like getting a good coach. Most of you accept a personal trainer or a basketball, tennis, or golf coach. You may need a coach to help with your wife's cancer.”

“I was so grateful to my wife for understanding that I sometimes felt resentful about the changes her cancer made in my life and our life together. We talked about it and she forgave me for what I know were selfish but I guess normal feelings.”