





Colorado Ovarian Cancer RESOURCE GUIDE

3rd Edition

Presented by

CO colorado ovarian
Ca cancer alliance
www.colorado-ovariancancer.org



The information and listings provided in this guide should not be construed as an endorsement or recommendation by the Colorado Ovarian Cancer Alliance. The content is for informational purposes only. Colorado Ovarian Cancer Alliance does not provide medical advice or endorse providers of medical services.

The information presented in this guide is not intended in any way to be a substitute for medical advice or professional counseling. Please always include your health care providers in any decisions you make regarding changes in nutrition, exercise routine, and before you include complementary, alternative or integrative care into your treatment regimen.

Sources are cited for information, and the descriptions of services are from the websites of those businesses or nonprofits included herein.



One Step at a Time

Every journey begins with a single step, followed by another and another. Remember that things will not always be this way, that the beginning only happens once and from thence forward you will continually gain more experience and understanding.

A Second Opinion?

Ovarian cancer is a serious diagnosis, so you may want to get a second opinion from another doctor. Check the list of Gynecologic Oncologists on page 14 for physicians who specialize in surgery and treatment for ovarian cancer.

Don't go it Alone



Getting a cancer diagnosis is a traumatic event, often leaving you dazed and feeling overwhelmed. Due to this effect, it is easy to miss many of the doctor's words and explanations, so it's best to not go alone to appointments. Have a spouse, family member or friend come along with a pad of paper and pencil, or even a recorder, so everything can be captured and you can review the doctor's words again at a later time.

How to be a Friend to a Friend who's sick

Your friends may not know how to respond when they hear you have cancer. Help them by suggesting this insightful book.

<http://amzn.com/1610393740>

Getting Started

Dealing with Diagnosis



Getting a diagnosis of ovarian cancer is not easy. You may have waited months before an accurate diagnosis was made. You may have been in surgery just days after hearing the news. Whatever your situation, it is a traumatic event. A journey of physical, mental and emotional healing must be undertaken, which is best done with support, patience and love.

WHAT TO DO

If you or your loved one has been diagnosed with ovarian cancer, we at COCA suggest four things:

- Find a gynecologic oncologist
- Join an informational support group
- Stay informed about treatments and clinical trials as you are able
- Don't spend TOO much time on the internet reading negative statistics

We feel it is important that you work with a ***gynecologic oncologist***, not just a gynecologist. A gynecologic oncologist has experience with ovarian cancer surgery and is well-informed about specific chemotherapy treatments.

We suggest you ***join an ovarian cancer informational support group*** where you can learn about resources and share support with other women. As far as we know, Nicki's Circle Ovarian Cancer Support Groups are the only ovarian cancer groups available in Colorado. If you live outside of the Denver area, we suggest you join one of our telephone groups. See pages 33-34 for more information on Nicki's Circle.

There is a lot of information available about ovarian cancer on the web. We suggest staying informed to the extent you are able, without becoming overwhelmed. We advise you take the information you find to your doctor's visits with you, to discuss with him/her. However, if you get depressed or overwhelmed with all of the statistics and details you read, ***moderate your exposure on the web.***

SOME TIPS TO GUIDE YOU AT THE OUTSET . . .

- See a Gynecologic Oncologist .
- Work with doctors you can talk to and trust.
- It's okay to get a second opinion.
- Write down questions before appointments.
- Bring a friend to appointments to take notes.
- Consider a tumor assay and/or molecular profiling at surgery.
- Get household assistance and/or meals delivered after surgery.
- Build a team of healthcare professionals.
- Utilize complementary therapies.
- Join an informational support group.



Ten Things To Do If You Suspect You Have Ovarian Cancer

Excerpts from the book, *Ovarian Cancer: Your Guide to Taking Control* by Kristine Conner and Lauren Langford, O'Reilly & Associates, Sebastopol CA, May 2003.

1: FIND A GYNECOLOGIC ONCOLOGIST.

Gynecologic oncologists are physicians who specialize in diagnosing and treating cancers that affect the female reproductive organs, such as the ovaries, cervix, and uterus. After completing four years of medical school and a residency in obstetrics and gynecology, they receive additional training that focuses specifically on the treatment of gynecologic cancers.... Research has shown that women with ovarian cancer who are treated by gynecologic oncologists tend to fare much better than those who are not. If you've already been operated on by a gynecologist or general surgeon, it is not too late to consult with a gynecologic oncologist. Gather all of your records together and make an appointment as soon as you can. The gynecologic oncologist can assess the quality of your treatment to date and help you plan out next steps. Your best bet is to find a specialist located at a major hospital or cancer center that treats large numbers of women with ovarian cancer. This should be relatively easy if you live within driving distance of a large metropolitan area. However, even if you live in a remote area without easy access to a gynecologic oncologist, you need to find a way to get yourself to one. It's that important.

2: UNDERSTAND THAT THE QUALITY OF YOUR SURGERY CAN MAKE A MAJOR DIFFERENCE.

It is critical that you work with a gynecologic oncologist because the quality and thoroughness of your initial surgery can make a major difference in how you do over the long-term. Surgery for ovarian cancer is tricky and requires special skill. Once the gynecologic oncologist confirms that there is a cancerous tumor on the ovary, she/he knows that there is a good chance that some of the cancer cells have spread to other organs within the abdomen and pelvis (the area from just under your lungs down to your pubic bone). [The doctor's] job is to determine where the cancer has spread and to remove as much of it as is possible-without making the surgery too risky for you. This requires skill and a sense of judgment that can only be developed by operating on many women with ovarian cancer. Study after study has shown that, the more cancer that is removed, the better the likelihood of long-term survival. While it is important to find a specialist you like and trust, right now your first priority should be to find one who is an excellent and experienced surgeon. Remember that your decision isn't permanent. You can always make a switch later if the relationship does not work out, for whatever reason.

#3. READ YOUR PATHOLOGY REPORT

In most cases, your doctor will be able to inform you right after surgery whether or not you have ovarian cancer. However, it will be several days before the pathology report, which is a detailed report on the findings, becomes available. Another specialist known as a pathologist will need to spend time examining samples of the cancer and other tissues removed during the surgery. Ask for a copy of your pathology report and read it. With a good medical dictionary and/or Internet access at hand, you should be able to figure out the meanings of unfamiliar medical terms. If there is anything you can't figure out, you can discuss it with your doctor. (Chapter 2 of *Ovarian Cancer: Your Guide to Taking Control* should help you as well.) Although this may seem like an intimidating exercise, there are many benefits to reading your pathology report. It gives you time to digest the information firsthand, rather than getting everything secondhand from your doctor. Among other things, the report will tell you whether the tumor is benign (not cancerous), malignant (clearly cancerous), or somewhere in between (a condition often referred to as Low Malignant Potential or atypical proliferative tumor); in what part of the ovary it originated; what the cell type is; and where any evidence of cancer spread was found. Reading the report also serves as a crash course in the terminology of ovarian cancer, which will prove helpful to you over time. Finally, reading this report can be a powerful way of taking charge of your situation. After all, the report has to do with your body, and you should have a full understanding of the situation. Simply requesting a copy lets your health care team know that you see yourself as a partner in your care.

4: SPEAK UP AND ASK QUESTIONS.

If this is your first experience with a serious illness, you're about to get a crash course in the realities of the American medical system. The most important lesson to learn right away is that time and resources are limited, and, in most cases, patients only get as much time, attention, and information as they ask for. So you want to be one of those patients who knows something about her diagnosis and asks questions. You don't have to get a medical degree or spend hours and hours in the library to educate yourself enough to ask intelligent questions. This book, *Ovarian Cancer: Your Guide to Taking Control*, combined with other information you find on your own, should be enough to get you started. As you skim through this book, check out the boxed "Questions to Ask Your Health Care Team" for ideas about what to ask when discussing various topics. In addition to asking questions about your disease and its treatment, ask about what services are available for people in your

situation. Most hospitals have a range of programs in place for people with cancer, or at the very least have close connections with community-based programs. Whether you're seeking educational seminars or support groups, financial or transportation assistance, information about nutrition and exercise, or something else, ask your health care team what's available. Again, this information might not be offered to you unless you ask for it.

5: CONNECT WITH ANOTHER OVARIAN CANCER SURVIVOR.

If you have done any reading about ovarian cancer, you probably have encountered a number of pamphlets that begin something like this: "Ovarian cancer is the most lethal of gynecologic cancers and the fourth leading cause of cancer death in American women." Yes, it is true that ovarian cancer is serious, and it does take many women's lives. But don't lose sight of the fact that there are many survivors out there, too. As a newly diagnosed woman, you may find it helpful to speak and/or meet with a woman who is now a few years out from the same diagnosis you've just received. In addition to giving advice, she can give you hope that you will be in her position a few years from now. There are different strategies you can use for finding such a person. [See pages 33-43 in this guide for local resources.] Your hospital, cancer center, or local cancer organizations may have organized a "buddy system" that matches survivors with new patients who have received similar diagnoses. You might try a support group for women with ovarian and other gynecologic cancers, which is likely to have some "veterans" in attendance. You also can try organizations such as the Ovarian Cancer National Alliance or the National Ovarian Cancer Coalition, which are headquartered in Washington, DC, and Florida, respectively, but have contacts in communities throughout the U.S. If you have Internet access and an e-mail account, you can join an online support group for women facing ovarian cancer and post your request there.

#6: CONSIDER CLINICAL TRIALS.

After surgery, most women with ovarian cancer need to undergo chemotherapy. Chemotherapy is intended to destroy any small deposits of cancer or microscopic cancer cells that may have been left behind after surgery. The standard treatment involves getting two drugs, carboplatin and Taxol, which have proven highly effective in the treatment of ovarian cancer. Most women do respond to them and go into remission, a period during which there is no evidence of any cancer. At the same time, however, these drugs usually do not offer a permanent solution: most women can expect their cancer to recur, or come back, at some point in the future. For this reason, some women decide that they want to enroll in a clinical trial, or a research study that involves patients. Some of these trials are comparing the current standard of care with newer treatments, such as different combinations of chemotherapy drugs and other anti-cancer treatments. Many women choose to take part because (1) they want to help the medical community in its quest to find a better treatment, and (2) they know that they may receive the newer treatment, which could end up being more effective than standard treatment. In fact, the first ovarian cancer patients who were treated with Taxol received the drug on a clinical trial. Many people mistakenly believe that clinical trials are for patients who have exhausted all other treatment options, but that is not true. You can choose to take part in a clinical trial at any point in your treatment. In fact, many of the women interviewed for this book said they would have considered a clinical trial for their first treatment if they had known that they were even an option! If you think you might be interested in a clinical trial, either now or at some point in the future, start educating yourself about them. Most trials place limits on the types and amounts of previous treatments that participants can have had. One of the best resources for getting started is the clinical trials section of the National Cancer Institute's (NCI) Web site, at <http://www.cancer.gov/about-cancer/treatment/clinical-trials>. There you can find more information about clinical trials and search for NCI-approved trials specific to ovarian cancer. If you don't have internet access, you can call the NCI at 1-800-4-CANCER and request information by mail.

7: GET ACCESS TO A COMPUTER WITH INTERNET ACCESS AND AN E-MAIL ACCOUNT.

If you don't have a computer and it's financially possible for you to get one, now would be a good time to do so. If you have a computer in your home but you don't use it very much, now is the time to start. Depending on your level of computer literacy, you may need to enlist the help of a family member or friend in this effort. There is an incredible wealth of information and support for people with cancer available on the Internet-and it's all free. While some of the information is of poor quality and downright misleading, the good far outweighs the bad. All of the major cancer-related organizations, including those that deal specifically with ovarian and other gynecologic cancers, have Web sites that feature quality information and practical advice, the latest cancer news, and in some cases, online message boards. You also can use the Web to learn more about doctors and cancer centers that have expertise in ovarian cancer, access current thinking about its treatment, and even read about the latest medical meetings on this disease. You also can connect with other patients who are online and going through the same experiences at the same time you are... If you're not able to get computer access on your own, enlist the help of family members or friends who are comfortable using the Internet to do the work for you. This is a good specific

assignment to give someone who asks if there is anything they can do to help. They can always print out whatever information they find and pass it along to you.

8: TAP INTO OVARIAN CANCER ORGANIZATIONS.

There are a number of organizations that are dedicated specifically to meeting the needs of women with ovarian and other gynecologic cancers. By tapping into their resources, you'll not only be able to start educating yourself, but you'll also discover that you are not alone in this experience.

9: INFORM YOUR FAMILY, FRIENDS, AND COWORKERS.

Just a generation ago, people often felt compelled to hide the news that they had cancer—or at least to hide the real diagnosis if it involved sexual or reproductive organs such as the ovaries, cervix, uterus, or breast in women, or the testicles or prostate in men. There is good reason to suspect that many women who were said to have “stomach cancer” in the early- to mid-twentieth century actually had ovarian cancer. People are much more open about cancer today, but some are still reluctant to share the news because they have a fear of being stigmatized or pitied or even isolated by others. While it will be difficult for you to share the news of your diagnosis with relatives, friends, and colleagues, it is best to be open and honest right away, for a number of reasons. First, you'll become part of the solution in moving cancer out of the closet and promoting awareness. There is no reason for you to feel ashamed or embarrassed. Second, there is often a family connection with ovarian cancer, and your diagnosis may indicate that other family members are at increased risk—especially if there are other cases of ovarian and/or breast cancer in the family. Finally, and perhaps most importantly, you may open yourself up to sources of support that you never could have imagined. Maybe your coworker's aunt is a gynecologic oncologist or a nurse on a gynecologic oncology unit. Maybe your boss's sister-in-law or your son's friend's mother is an ovarian cancer survivor. You never know who might be a source of good information and support during this time. Also, if people know what you are going through, they often will take the initiative to help—by taking on some of your workload, stocking your freezer with prepared meals, running errands, and so forth.

10: IF YOU NEED PROFESSIONAL HELP IN ORDER TO COPE, GET IT.

Anyone who faces a cancer diagnosis experiences a certain amount of depression and anxiety. But for some people, these feelings become absolutely overwhelming; they can't eat, sleep, or function at a level that is anywhere close to normal. They feel completely helpless and simply can't find a way to turn things around. They become so depressed, so anxious, that they can't take action in any kind of a productive way. If you find yourself in this situation, don't be afraid to seek professional help. Your health care team may be able to refer you to a mental health professional who specializes in working with people who have cancer. Many women find it helpful to meet with such a professional and, if necessary, take anti-depressant or anti-anxiety medication to help them get through the most difficult early period. If therapy and/or medications are what you need to function at a level that is close to normal, you should not hesitate to seek them out. Your health care team should not be surprised to hear this request.

Excerpt from: www.oreilly.com/medical/news/ovarian_ten_things.html

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The Cancer Survival Toolbox

“Full of practical tips and strategies.... Information for people at any stage of cancer survivorship — newly diagnosed, undergoing treatment, transitioning to new treatments or off treatment, and beyond.

READ THE BOOKLET ONLINE:

www.canceradvocacy.org/wp-content/uploads/2013/02/Cancer-Survival-Toolbox-Resource-Booklet.pdf

LISTEN ONLINE:

Learn from survivors as they share their experiences, skills, and resources.

www.canceradvocacy.org/resources/cancer-survival-toolbox/

EN ESPAÑOL: www.canceradvocacy.org/shop/cancer-survival-toolbox-esp/

Produced through a unique collaboration between the National Coalition for Cancer Survivorship (NCCS), the Oncology Nursing Society, and the National Association of Social Workers, with a grant from Genentech, Inc., the Toolbox encourages people with cancer and their caregivers to take a more active role in their care. The Toolbox is available in English and Spanish.”

Gynecologic Oncology



Experts at the National Comprehensive Cancer Network (NCCN) [see below] recommend that ovarian cancer surgery and staging be done by a gynecologic oncologist.**

from the NCCN Guidelines for Patients – Ovarian Cancer
www.nccn.org/patients/guidelines/ovarian/#28/z

★ *****The National Comprehensive Cancer Network® (NCCN®), is a not-for-profit alliance of 27 of the world's leading cancer centers... [that] recognizes the significance of creating clinical practice guidelines appropriate for use by patients, clinicians, and other health care decision-makers.** www.nccn.org/about/

Who is a Gynecologic Oncologist?

Gynecologic Oncologists are specially trained in surgical methods that ensure an optimal “de-bulking” of ovarian cancer. They spend extra time in surgery clearing as much tumor material as possible. Surgeons in other specialties do not have the same training and may not carry out a complete de-bulking. In addition, gyn oncologists stay current with the latest chemotherapies being used against ovarian cancer.

Gynecologic Oncology

According to the Society of Gynecologic Oncology (SGO)

“A gynecologic oncologist is a physician who specializes in diagnosing and treating cancers that are located on a woman's reproductive organs. Gynecologic oncologists have completed obstetrics and gynecology residency and then pursued subspecialty training through a gynecologic oncology fellowship. Residency takes four years to complete, while fellowship involves three to four additional years of intensive training about surgical, chemotherapeutic, radiation, and research techniques that are important to providing the best care for gynecologic cancers. Physicians who complete this training are eligible to take both the obstetrics

and gynecology board exam and the gynecologic oncology board exam. The gynecologic oncologist serves as the captain of a woman's gynecologic cancer care team. It is important to consult with a gynecologic oncologist before treatment is started so that the best treatment regimen is chosen for you.”

www.sgo.org/patients-caregivers-survivors/what-is-a-gynecologic-oncologist/

Gynecologic Oncology for Ovarian Cancer

According to the Society of Gynecologic Oncology (SGO)

“Gynecologic oncologists are trained in the comprehensive management of gynecologic cancer. As such, they coordinate care for women with ovarian cancer from diagnosis, to surgery, to chemotherapy, through survivorship and palliative care at the end of life. They serve as captain of the entire cancer care team of medical oncologists, pathologists, radiologists, physician assistants, nurse practitioners, registered nurses and genetic counselors, among others.”

www.sgo.org/ovarian-cancer

Medical Oncology

Some hospitals and healthcare systems provide a gynecologic oncologist for ovarian cancer surgery and a medical oncologist for chemotherapy treatment.

from the National Cancer Institute (NCI)

According to the NCI Dictionary of Cancer Terms, a medical oncologist is: “A doctor who specializes in diagnosing and treating cancer using chemotherapy, hormonal therapy, biological therapy, and targeted therapy. A medical oncologist often is the main health care provider for someone who has cancer. A medical oncologist also gives supportive care and may coordinate treatment given by other specialists.”

www.cancer.gov/publications/dictionaries/cancer-terms?cdrid=46290

COCA may be able to help you pay for a visit to a Gyn Oncologist. See COCACares info on page 44.



Standard of Care for Ovarian Cancer - The Issue

from the Ovarian Cancer Research Fund Alliance

“In 2013, Dr. Robert Bristow from the University of California, Irvine, published a study showing that only 37.2 percent of patients actually received care that adhered to NCCN** [see above] clinical practice guidelines. NCCN guidelines dictate that women should have their surgery and staging done by a gynecological oncologist, as well as the correct chemotherapy regimen they should undergo. Women who don't receive standard of care have a 30 percent greater risk of dying within five years of diagnosis than those who do. Typically, women who were treated at large, high-volume hospitals received standard of care, whereas those treated at low-volume hospitals did not. Additional research studies have shown that women from low-income or minority backgrounds typically have poorer survival rates. The results of this study were widely reported in the news, hopefully drawing the attention of physician's organizations and patients to this serious issue.”

www.ovariancancer.org/what-we-do/policy-positions/standard-of-care/

Gynecologic Oncologists in Colorado



★ NCCN** experts recommend that you have a Gynecologic Oncologist perform surgery if you have been diagnosed with ovarian cancer. (see page 13)

Dr. Kian Behbakht, M.D.

University of Colorado, Aurora, CO
80045 303.724.2066

www.cudoctors.com/find-a-doctor/profile/?providerID=2040&keywords=behbakht

www.healthgrades.com/physician/dr-kian-behbakht-2c3nh

Dr. Glenn Bigsby, D.O.

The Colorado Center for Gynecologic Oncology, Littleton, CO 303.955.7574
<http://ccgynonc.com/glenn-bigsby-iv-do/>

www.healthgrades.com/physician/dr-glenn-bigsby-xlptl

Dr. Bradley Corr, M.D.

Starting Fall 2016
University of Colorado, Aurora, CO
80045 303.724.2066

Dr. Susan A. Davidson, M.D.

Denver Health Medical Center
Denver, 80204 303.436.6000
<http://physicians.denverhealth.org/Details/1241?Index=16>
www.healthgrades.com/physician/dr-susan-davidson-2r4mm

Dr. Kevin P. Davis, M.D.

Rocky Mountain Gynecologic Oncology,
Englewood, CO 80113 303.781.9090
www.gyn-onc.org/RMGO-Providers.html
www.healthgrades.com/physician/dr-kevin-davis-x6k7k

Dr. Daniel Michael Donato, M.D.

Rocky Mountain Cancer Center
Denver, CO 80220 303.321.0302
www.rockymountaincancercenters.com/providers/daniel-donato/

www.healthgrades.com/physician/dr-daniel-donato-xwhrt

Dr. Saketh Guntupalli, M.D.

University of Colorado, Aurora, CO
80045 303.724.2066

www.cudoctors.com/find-a-doctor/profile/?providerID=4684&keywords=Guntupalli

www.healthgrades.com/physician/dr-saketh-guntupalli-yjyf5

Dr. Ruth E. Higdon, M.D.

Grand Valley Oncology,
Grand Junction, CO 81501
970.254.3180

<http://grandvalleyoncology.com/www.healthgrades.com/physician/dr-ruth-higdon-yn4w9>

Dr. Jeffrey James, D.O.

The Colorado Center for Gynecologic Oncology, Littleton, CO 303.955.7574
<http://ccgynonc.com/jeffrey-james-do/>

www.healthgrades.com/physician/dr-jeffrey-james-y9bdp

Dr. Carolyn Lefkowitz

University of Colorado, Aurora, CO
80045 303.724.2066

www.cudoctors.com/Find_A_Doctor/Profile/23055

www.healthgrades.com/physician/dr-carolyn-lefkowits-23wlc

Dr. Dirk Pikaart, D.O.

Southern Colorado Gynecologic Oncology, Colorado Springs, CO 80907
719.776.6222

<http://coloradogynonc.com/providers.php>
www.healthgrades.com/physician/

[dr-dirk-pikaart-3cy2x](http://www.healthgrades.com/physician/dr-dirk-pikaart-3cy2x)

Dr. Jennifer Rubatt, M.D.

Banner Health McKee Medical Center,
Loveland, CO 80538
970.820.5900

<http://www.bannerhealth.com/banner+medical+group/office+locations/banner+health+clinic+-+oncology+-+greeley+sterling/Our+Providers/Provider+Detail.htm?pid=1321>
www.healthgrades.com/physician/dr-jennifer-rubatt-333g6

Dr. Mary Jo Schmitz, M.D.

Rocky Mountain Gynecologic Oncology,
Englewood, CO 80113 303.781.9090
www.gyn-onc.org/RMGO-Providers.html
www.healthgrades.com/physician/dr-mary-jo-schmitz-39ln8

Dr. Pamela J.B. Stone, M.D.

SCL Health - Lafayette & Denver CO
80303 303.318.3214
www.sclphysicians.org/find-a-doctor/s/stone-pamela-jl
www.healthgrades.com/physician/dr-pamela-stone-y9qkb

Colorado Kaiser Permanente

2045 Franklin Street, Denver, CO 80205
303.764.5530

Dr. Margrit M. Juretzka, M.D.

www.healthgrades.com/physician/dr-margrit-juretzka-2mgbk

Dr. Julia Embry-Schubert, M.D.

www.healthgrades.com/physician/dr-julia-embry-3nvwj

Dr. Sarah Whittier, M.D.

www.healthgrades.com/physician/dr-sarah-czok-ymcnq