

# Ovarian Cancer Resource Guide

Produced by:  
Rhode Island Ovarian Cancer Alliance



## About Us

The Rhode Island Ovarian Cancer Alliance (RIOCA) was formed in honor/memory of Jessica Morris. Jessica was diagnosed with Stage IIIC Ovarian Cancer just two weeks after her 18th birthday in October 2005. She underwent a full hysterectomy followed by several rounds of chemotherapy. It was at this point Jessica made it her mission to educate and raise awareness about ovarian cancer. Within a month of her surgery, she was back at Lincoln High School, educating her former classmates about ovarian cancer symptoms and warning signs.

Several months after Jessica completed her chemotherapy her cancer returned. The next couple of years Jessica continued her battle going through additional surgeries and treatments. On August 29, 2008, surrounded by family and friends Jessica lost her courageous battle.

When Jessica was first diagnosed it became her mission to educate and raise awareness about this horrific disease. We partnered with a national organization back in 2007 to bring education and awareness to the state of Rhode Island since there was no local ovarian cancer organization.

In December 2015, we separated from the national organization and formed the Rhode Island Ovarian Cancer Alliance

We are a 501(c)(3) non-profit organization

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## Our Mission

Rhode Island Ovarian Cancer Alliance (RIOCA) strives to, educate and raise awareness about ovarian cancer for earlier detection. Provide support and resources to ovarian cancer survivors and their families with a grass roots effort led by inspired and passionate people.

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## Information

The information and listings provided in this guide should not be construed as an endorsement or recommendation by Rhode Island Ovarian Cancer Alliance (RIOCA). The content is for informational purposes only. Rhode Island Ovarian Cancer Alliance (RIOCA) 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.

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# Rhode Island Ovarian Cancer Alliance - Programs

## Our Support Programs

RIOCA offers support programs to help women and caregivers through the ovarian cancer journey.

### RIOCA Totes of Hope

Totes of Hope are provided to women who are newly diagnosed and in treatment. The tote is filled with helpful information and useful products to assist women as they begin their journey.

### RIOCA Resource Guide

This resource guide is published as a support service to patients/survivors. It is also available to download from our website

### Teal Meals

RIOCA will offer meals once a month for several months as women is going through treatment. To learn more or apply for the meal service, visit our website.

### House Cleaning (Coming Soon)

RIOCA will arrange for a general cleaning of a home once during treatment. To learn more or apply for the cleaning service, visit our website.

## Our Education and Awareness Programs

RIOCA works to educate the public and healthcare providers about ovarian cancer symptoms and risk factors.

### Health Fairs

RIOCA raises awareness at health fairs and expos throughout the year, with special efforts during September

### September Awareness – Silent No More 5K

RIOCA's Annual 5K Run/Walk to raise awareness of ovarian cancer and support our mission and programs

### Survivors Teaching Students: Saving Women's Lives®

As a Community Partner of the Ovarian Cancer Research Fund Alliance (OCRFA), local ovarian cancer survivors present their stories to students at University of Connecticut, Tufts Medical School, Maine Medical and Maine College of Health Professions (page 43)

### Speaking Events

A presentation that educates women and loved ones on how to recognize the subtle symptoms, assess their personal risk and seek proper medical attention for the best outcome. It's a great presentation for health fairs and conference sessions, service and religious groups, etc. Contact us at [info@riovarian.org](mailto:info@riovarian.org) or 401-400-0333

# Getting Started

## 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 someone 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

## What is Ovarian Cancer

Ovarian Cancer is a disease in which malignant (cancerous) cells grown in one or both of the ovaries, which are part of a woman's reproductive system. An ovary is one of two almond-sized female reproductive organs located on either side of the uterus. The ovaries produce eggs (ova), as well as the female hormones, estrogen and progesterone. Malignant cells in the ovaries can spread to other parts of the body (metastasize) either directly to other organs in the pelvis and abdomen or through the bloodstream or lymph nodes to other parts of the body.

## 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.

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.

One thing you should know is that you are not alone. The Rhode Island Ovarian Cancer Alliance is here to support you, your family and caregivers through your journey.

## What to do

If you or your loved one has been diagnosed with ovarian cancer, we at RIOCA 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 to 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.

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 suggest you take the information you find to your doctor's visits to discuss with him/her.

# Gynecologic Oncology

## Who is a Gynecologic Oncologist?

Gynecologic Oncologists are specially trained in surgical methods that ensure an optimal “debulking” 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 debulking. 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](http://www.sgo.org/patients-caregivers-survivors/what-is-a-gynecologic-oncologist)

## Medical Oncology

Some hospitals and healthcare systems provide a gynecologic oncologist for ovarian cancer surgery and a medical oncologist for chemotherapy treatment. 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](http://www.cancer.gov/publications/dictionaries/cancer-terms?cdrid=46290)

## 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](http://www.sgo.org/ovarian-cancer)

# Gynecologic Oncology

## Questions to ask your doctor

The National Cancer Institute suggests a patient might ask a doctor the following questions before starting treatment:

- What is the stage of my cancer?
- Has the cancer spread from the ovaries to other areas of my body? If so, where?
- Has all my cancer been removed?
- What are the ways to treat my stage of cancer? What are the benefits and risks of each?
- How many chemotherapy sessions will I need? How long is each session?
- When will I need to start treatment?
- Will I need to be in the hospital for treatment? If so, for how long?
- What side effects will I have from chemotherapy? Is there anything I can do to alleviate them?
- Would a clinical trial (research study) be right for me?
- Can I get chemotherapy at my local hospital since it is too far to get to a major medical center?
- Will my insurance cover the cost of treatment?
- How will the treatment affect my normal activities?
- What are my chances of recovery with this treatment?
- Will the treatment cause me to go through early menopause?
- How often will I need to go for checkups after my treatment ends?
- How often should I have a CA-125 assessment?

### Additional things to consider

- Prepare your questions in advance of your appointment.
- Don't be shy, every question you have is important.
- Be sure to prioritize your questions to be sure you can discuss the most important ones first.
- Bring someone with you to help you document what the doctor says. It can be difficult to concentrate and remember information when you visit.
- It's ok to ask the doctor to simplify the explanations
- Be your own advocate

If you don't feel comfortable with a doctor, or want to get a second opinion about treatment options, you have the right to do this. In fact, most medical professionals expect a patient to get a second opinion.





# Gynecologic Oncologists in Rhode Island

<p><b>Dr. Christina Bandera, MD</b> Women's Medicine Collaborative 146 W. River Street Suite 11C Providence, RI 02904 (401) 793-7836</p>	<p><b>Dr. Paul Disilvestro, MD</b> Women &amp; Infants Hospital 101 Dudley Street Providence, RI 02905 (401) 453-7520</p>	<p><b>Dr. Katina Robison, MD</b> Women &amp; Infants Hospital 101 Dudley St Providence, RI 02905 (401) 453-7520</p>
<p><b>Dr. Cara Mathews, MD</b> Women &amp; Infants Hospital 101 Dudley Street Providence, RI 02905 (401) 453-7520</p>		<p><b>Dr. Anne Shapter, MD</b> Lahey Clinic 100 Wayland Ave Apt. 7 6th Floor Providence, RI 02906 (781) 744-2933</p>
<p><b>Dr. Matthew Oliver, MD</b> Women &amp; Infants Hospital 101 Dudley St Providence, RI 02905 (401) 453-7520</p>	<p><b>Dr. Ashley Stuckey, MD</b> Women &amp; Infants Hospital 101 Dudley St Providence, RI 02905 (401) 453-7520</p>	<p><b>Dr. Elizabeth Lokich, MD</b> Women &amp; Infants Hospital 101 Dudley St Providence, RI 02905 (401) 453-7520</p>

You can also find such a specialist in your area by searching the Foundation of Women's Cancer national list of Gynecologic Oncologists at [www.foundationforwomenscancer.org](http://www.foundationforwomenscancer.org) or by calling 1-312-578-1439

## Questions to Consider When Choosing Your Doctor

- Is your doctor a gynecologic oncologist
- Is he/she experienced in treating your kind of ovarian cancer
- Does the doctor accept your insurance
- Do you find it easy to communicate freely with him/her
- Is the doctor's staff nice, helpful and responsive
- Does the doctor have a good reputation among other doctors and patients
- Does he/she administer chemotherapy

# Ovarian Cancer Facts

## Ovarian Cancer Cell Types

There are more than 30 different types of ovarian cancer, classified by the type of cell from which they originate. The three most common types of cells can develop into a different type of tumors:

- Epithelial tumors – Approximately 90 percent of ovarian cancers develop in the epithelium, the thin layer of tissue that covers the ovaries and makes up the fallopian tubes. This form of ovarian cancer generally occurs in postmenopausal women.
- Germ cell carcinoma tumors - Approximately five percent of ovarian cancer cases begin in the cells that form eggs. While germ cell carcinoma can occur in women of any age, it is found most often in women who are in their early 20s. Many tumors that arise in the germ cells are benign.
- Stromal carcinoma tumors - Ovarian stromal carcinoma accounts for about five percent of ovarian cancer cases. It develops in the connective tissue cells that hold the ovary together and those that produce the female hormones estrogen and progesterone. The two most common types are granulosa cell tumors and sertolileydig cell tumors. Unlike with epithelial ovarian carcinoma, 70 percent of stromal carcinoma cases are diagnosed in stage I.

## Ovarian Cancer Grading

The grade of a cancer means how the cells look under the microscope. The appearance of the cells gives doctors an idea of how quickly or slowly the cancer is likely to grow. There are three grades of ovarian cancer:

- Grade 1 or well differentiated
- Grade 2 or moderately differentiated
- Grade 3 or poorly differentiated (or undifferentiated)

As a normal cell grows and matures, it becomes specialized for its role and place in the body. This is called differentiation. Cancer cells can look like normal cells and are described as well differentiated or low grade. If the cancer cells look underdeveloped and nothing like a normal cell, they are known as undifferentiated or high grade. These cancers tend to grow and spread more quickly than low grade cancers.

## Ovarian Cancer Staging

Ovarian cancer staging is determined by your doctor at the time of surgery. The different stages describe the level of tumor cell involvement and how widespread the cancer is. Women with ovarian cancer are frequently diagnosed at Stage IIIC. This is because the symptoms of ovarian cancer are often ignored or misdiagnosed until urgent issues arise

### Stage I

Tumor confined to ovaries and considered an early cancer

#### Stage IA

Cancer cells are present in one ovary or fallopian tube

#### Stage IB

Cancer cells are present in both ovaries, or in both fallopian tubes

#### Stage IC

Cancer cells are present in one or both ovaries and/or fallopian tubes, and one of the following:

- The outside of the ovaries or fallopian tubes has cancer cells;
- The covering of the ovary, called the capsule, has broken open; or
- Cancer cells are found in your peritoneal cavity, its tissue lining, or fluid from your abdomen

### Stage II

Cancer has begun to spread

#### Stage IIA

Cancer has spread from the ovary or ovaries to the fallopian tubes and/or the uterus, or it has spread from the fallopian tubes to the ovaries and/or uterus

#### Stage IIB

Cancer has spread in the peritoneal cavity to your bladder, colon, or rectum

### Stage III

Cancer is more advanced

#### Stage IIIA1

Cancer cells have spread to the closest lymph nodes, called the retroperitoneal lymph nodes

#### Stage IIIA2

Cancer cells have spread to the outside the pelvis to the peritoneum (lining). The cancer may also have spread to nearby lymph nodes

#### Stage IIIB

Cancer inside the peritoneum can be seen by the surgeon, but is still 2 centimeters or smaller. The cancer has also spread outside the pelvis. It may have spread to nearby lymph nodes

#### Stage IIIC

Cancer has grown to 2 centimeters in diameter or larger, and has spread to the peritoneum outside the pelvis. It may also have spread the outside of the liver and/or the spleen, as well as nearby lymph nodes

## Stage IV

Cancer is the most advanced form of ovarian cancer

### Stage IVA

Cancer cells are found in extra fluid that has built up around the lungs

### Stage IVB

Cancer has reached the inside of the spleen or liver, distant lymph nodes, or to other distant organs such as skin, lungs, or brain.

## Genetic Testing

Women diagnosed with Epithelial Ovarian, Tubal, and Peritoneal Cancers should receive genetic counselling and be offered genetic testing even in the absence of a family history.

### What caused your Ovarian Cancer?

Medical professionals do not know exactly what causes ovarian cancer. The single biggest risk factor for ovarian cancer is heredity. Approximately 5 to 10 percent of women diagnosed have a family history of the disease in one or more first-degree relatives (grandmother, mother, aunt, sister, daughter from either side of the family). A family history of cancers of the breast, colon, uterus or rectum may also increase a woman's risk.

The most significant risk factor for ovarian cancer is inheriting a defect in breast cancer susceptibility (BRCA) genes. Normally these genes help to prevent cancer, but if a woman has developed a mutation in the BRCA1 or BRCA2 gene, her ovaries and breasts are more susceptible to the development of cancer. Studies show that inheriting a defect in these genes increases the risk of ovarian cancer by 10 to 20 percent. Women of Eastern European and Ashkenazi Jewish descent are at higher risk of carrying BRCA1 and BRCA2 mutations. Men can also be carriers of the BRCA1 and BRCA2 genes and can therefore pass the genes down to their children. Keep in mind that not everyone who inherits a BRCA gene mutation will develop cancer.

### Is Genetic Testing Right for you?

from National Cancer Institute (NCI)

Genetic testing looks for specific inherited changes mutations in a person's chromosomes, genes, or proteins. Genetic mutations can have harmful, beneficial, neutral ((no effect), or uncertain effects on health. Mutations that are harmful may increase a person's chance, or risk, of developing a disease such as cancer. Overall, inherited mutations are thought to play a role in about 5 to 10 percent of all cancers. The genetic mutations that cause many of the known hereditary cancer syndromes have been identified, and genetic testing can confirm whether a condition is, indeed, the result of an inherited syndrome.

Genetic testing is also done to determine whether family members without obvious illness have inherited the same mutation as a family member who is known to carry a cancer-associated mutation. Inherited genetic mutations can increase a person's risk of developing cancer through a variety of mechanisms, depending on the function of the gene. Mutations in genes that control cell growth and the repair of damaged DNA are particularly likely to be associated with increased cancer risk.

**It is recommended that you speak with a trained Genetic Counselor to determine the need for and direction of genetic testing.**

[www.cancer.gov/about-cancer/causes-prevention/genetics/genetic-testing-fact-sheet#q1](http://www.cancer.gov/about-cancer/causes-prevention/genetics/genetic-testing-fact-sheet#q1)

## Genetic Counseling and Test Results

from National Cancer Institute (NCI)

It is strongly recommended that a person who is considering genetic testing speak with a professional trained in genetics before deciding whether to be tested. Genetic counseling can help people consider the risks, benefits, and limitations of genetic testing in their particular situation. Sometimes the genetic professional finds that testing is not needed. Genetic counseling includes a detailed review of the individual's personal and family medical history related to possible cancer risk. Counseling also includes discussions about such issues as:

- 1) Whether genetic testing is appropriate, which specific tests) might be used, and the technical accuracy of the tests)
- 2) The medical implications of a positive or a negative test result
- 3) The possibility that a test result might not be informative (that is, that the information may not be useful in making health care decisions)
- 4) The psychological risks and benefits of learning one's genetic test results
- 5) The risk of passing a genetic mutation (if one is present in a parent to children)

[www.cancer.gov/about-cancer/causes-prevention/genetics/genetic-testing-fact-sheet](http://www.cancer.gov/about-cancer/causes-prevention/genetics/genetic-testing-fact-sheet)

People considering genetic testing must understand that their results may become known to other people or organizations that have legitimate, legal access to their medical records, such as their insurance company or employer, if their employer provides the patient's health insurance as a benefit. However, legal protections are in place to prevent genetic discrimination, which would occur if insurance companies or employers were to treat people differently because they have a gene mutation that increases their risk of a disease such as cancer or because they have a strong family history of a disease such as cancer. In 2008, the Genetic Information Nondiscrimination Act (GINA) became federal law for all U.S. residents. GINA prohibits discrimination based on genetic information in determining health insurance eligibility or rates and suitability for employment.”

**From:** [www.genome.gov/10002077](http://www.genome.gov/10002077) **Also see:** [www.ginahelp.org](http://www.ginahelp.org)

# Ovarian Cancer Treatment

Women should always discuss treatment options with a physician because optimal treatment will depend on the stage of the disease, the woman's age, her general health and her desire to have children. The main treatment choices for Ovarian Cancer are:

- **Surgery:** During surgery, doctors try to remove as much of the visible cancer as possible (tumor debulking). Women who have the surgery performed by a gynecologic oncologist have seen outcomes including improved survival and longer disease-free periods than those whose surgeons were general gynecologists or other surgeons inexperienced in optimal debulking procedures.
- **Chemotherapy:** After surgery, a woman will usually be advised to undergo chemotherapy, in an effort to destroy any cancer cells both in and outside the ovaries.
- **Radiation:** Radiation therapy uses high-energy X-rays to shrink tumors and kill cancer cells. It is rarely used in the treatment of Ovarian Cancer.
- **Clinical trials:** Many people think clinical trials, research studies that follow a predefined set of procedures, are only for those whose treatments have failed. However a woman is eligible to participate in a clinical trial at any point: before, during or after treatment. Clinical trials can often provide the latest and most innovative medicine that experts think might help improve an individual's cancer outcome. To learn more, go to [ClinicalTrials.gov](https://ClinicalTrials.gov).

Repeated studies have shown that treatment performed by a gynecologic oncologist significantly improves a woman's chance of survival and decreases rates of recurrence. Gynecologic oncologists are not only skilled surgeons, but they have extensive and specialized training in cancers of the reproductive system. Some studies show survival rates as much as 50 percent greater, compared to surgeries performed by surgeons less experienced in ovarian cancer treatment techniques.

## Managing Treatment

It is completely normal to feel anxious especially when you begin treatment and do not know what to expect. If you and your doctor have chosen chemotherapy, you need to be prepared for the physical and mental challenges that treatment may bring.

**Chemotherapy (chemo)** is the use of drugs to treat cancer. Most often, chemo is a systemic treatment the drugs are given in a way that lets them enter the bloodstream and reach all areas of the body. Systemic chemo can be useful for cancers that have metastasized (spread). Most of the time, systemic chemo uses drugs that are injected into a vein (IV) or given by mouth. It is common to undergo minor surgery to have a port placed under the skin in the clavicle area for IV chemotherapy. The port helps to keep veins in the arm viable and makes it easier for chemo nurses to administer drugs and take blood samples. For some cases of ovarian cancer, chemotherapy may also be injected through a catheter (thin tube) directly into the abdominal cavity. This is called intraperitoneal (IP) chemotherapy. Drugs given this way are also absorbed into the bloodstream, so IP chemotherapy is also a type of systemic chemo.

Chemo for ovarian cancer is most often a combination of 2 or more drugs, given IV every 3- to 4-weeks. Giving combinations of drugs rather than just one drug alone seems to be more effective in the initial treatment of ovarian cancer. The standard approach is the combination of a platinum compound, such as cisplatin or carboplatin, and a taxane, such as paclitaxel (Taxol®) or docetaxel (Taxotere®). For IV chemotherapy, most doctors favor carboplatin over cisplatin because it has fewer side effects and is just as effective. The typical course of chemo for epithelial ovarian cancer involves 3 to 6 cycles. A cycle is a schedule of regular doses of a drug, followed by a rest period. Epithelial ovarian cancer often shrinks or even seems to go away with chemo, but the cancer cells may eventually begin to grow again. If the first chemo seemed to work well and the cancer stayed away for a long time (at least 6 to 12 months), it can be treated with additional cycles of the same chemotherapy used the first time.

Chemotherapy drugs kill cancer cells but also damage some normal cells. Therefore, your doctor will be careful to avoid or minimize side effects, which depend on the type of drugs, the amount taken, and the length of treatment.

Common temporary side effects include;

- Nausea and vomiting
- Fatigue
- Loss of appetite
- Loss of hair
- Hand and foot rashes and mouth sores.

Chemotherapy can damage the blood-producing cells of the bone marrow, so patients may have low blood cell counts. This can result in increased chance of infection (caused by a shortage of white blood cells), bleeding or bruising after minor cuts or injuries (caused by a shortage of blood platelets), fatigue (caused by low red blood cell counts).

Most side effects disappear once treatment is stopped. Hair will grow back after treatment ends, although it may look different. There are remedies for many of the temporary side effects of chemotherapy. For example, drugs can be given to prevent and treat nausea and vomiting.

It is important to tell your doctor and oncologist about any side effects you develop so they can prescribe any medication that is needed.

You may also refer to American Cancer Society - A guide to chemotherapy

[http://jgh.ca/uploads/gynonc/chemo/guide%20to%20chemotherapy\\_ACS.pdf](http://jgh.ca/uploads/gynonc/chemo/guide%20to%20chemotherapy_ACS.pdf)

## Questions to ask your doctor about treatment

- Who will be administering the treatment and where?
- How often will treatment occur?
- How long will my treatment last?
- Will I be able to drive after treatment?
- Can I eat before I have treatment?
- Can someone accompany me or stay with me during treatment?
- Will I need to stay in the hospital after treatment?
- Can you provide detailed information about the treatment?
- What will happen?
- How will I feel?
- Will there be immediate or long-term side effects?
- Can I work during treatment?
- Does my health insurance cover treatment?

## NIH Booklet Chemotherapy and You

“Chemotherapy and You” is written for you—someone who is about to receive or is now receiving chemotherapy for cancer. Your family, friends, and others close to you may also want to read this book. This book is a guide you can refer to throughout your chemotherapy treatment. It includes facts about chemotherapy and its side effects and also highlights ways you can care for yourself before, during, and after treatment.”

[www.cancer.gov/publications/patient-education/chemotherapy-and-you.pdf](http://www.cancer.gov/publications/patient-education/chemotherapy-and-you.pdf)

## Chemotherapy.com

“Whether you’re preparing for your chemotherapy journey or managing the side effects, we have the information you need...every step of the way.”

## Chemocare.com

“Find the latest information about chemotherapy drugs including how they work, their potential side effects, and self-care tips while on these therapies.”



## Hair Loss with Chemo

Paclitaxel (i.e. Taxol) is the first-line chemotherapy drug generally given for ovarian cancer that causes sudden hair loss. Other chemotherapy drug agents may also cause hair loss or thinning. Many women choose to shave their heads before chemo begins. Others choose to cut their hair very short and others want to hold on to what they have for as long as they can. There is no right answer. Only you know what is right for you. Based on your treatment protocol, your doctor can give you an idea of when hair loss is expected to happen. When that time arrives, wear a shower cap or tight fitting cap to bed so you do not end up with hair all over your pillow in the morning. Take a brush or comb into the shower each day and gently comb or brush your hair as you rinse it. Also, take a plastic bag into the shower with you for holding the hair that does fall out. Celebrate when treatment is over and your fuzzy hair appears. Remember, you will likely lose your eyebrows and eyelashes as well.

It may be possible to reduce the loss of your hair by using a “cold cap” during chemotherapy treatment. Ask your doctor if it is okay to use one while undergoing your chemotherapy drug.

<https://www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/hair-loss/coping-with-hair-loss.html>

### Wigs, Hats & Scarves - American Cancer Society

ACS produces the "TLC - Tender Loving Care" catalog that features many wigs, hats, etc. at reasonable prices.  
[www.tlcdirect.com](http://www.tlcdirect.com)

In addition, ACS sponsors "Look Good, Feel Better" programs at local hospitals and clinics where you can get free makeup and wig assistance. [www.lookgoodfeelbetter.org](http://www.lookgoodfeelbetter.org)

### Headcovers Unlimited

“We are here to empower cancer patients and individuals with hair loss by providing quality products that allow individuals to feel like themselves again.” [www.headcovers.com](http://www.headcovers.com)

### Knots for Hope

“It's our wish that our resources on how to tie a head scarf will help women who have experienced hair loss feel confident and beautiful.” [www.scarves.net/blog/knots-for-hope](http://www.scarves.net/blog/knots-for-hope)

### Tips from a Survivor

Tips from Jeanene Smith, Colorado Ovarian Cancer Alliance Associate Director and 17 year ovarian cancer survivor **PRE-SURGERY / PRE-CHEMO TIPS**

- Set up a phone tree of people who need to know how you're doing and or a service such as [mylifeline.org](http://mylifeline.org) (see page 30) to keep people informed without having to make a multitude of calls.
- Plan ahead! Before you have surgery or chemo, take care of things that you might not have the energy to do after chemo begins:
- Take your children and or pets in for checkups.

- Get your car serviced
  - Go to the dentist BEFORE you begin chemo. Most doctors will advise AGAINST going to the dentist while you are in chemo due to risk of infection.
  - Get a pedicure (and manicure!) BEFORE chemo begins.
  - Stock your pantry and refrigerator with easy to prepare food and snacks.
  - Consider buying items that are a bit more bland. Your taste buds may change during chemo.
  - Cook a few meals ahead (or ask family and friends to help) for the freezer. There will be days you will not feel like cooking.
  - Purchase any heavy or bulky items (pet food, paper products, etc.)
  - Make it easy on yourself and buy a big pillbox to manage any medications that you might be given to combat side effects.
- 
- Consider purchasing (or borrowing) a comfortable reclining chair - very beneficial as you recover from surgery and go through chemo.
  - Make sure caregivers have keys to your home.
  - Make a checklist of bills you regularly pay and when they are due so you don't miss any payments.

## Post Surgery and During Chemo Tips

### Doctors' visits:

- Write any questions down in advance of your appointment.
- Always take someone with you to take notes and ask questions that you might forget
- Do not be afraid to question your doctor, it is your health, your life, and you are the customer) but remember, your doctor is your best ally.
- It is OK to seek a second opinion.

### Keep Medical Records:

- Consider keeping a 3-ring binder to house your doctor visit notes, questions for the doctor, blood test, results, CT Scan reports, and a journal where you track daily how you are feeling physically and emotionally.

### Listen to your body:

- If you are tired, rest.
- If you are in pain, report it to your doctor. Do NOT try to tough it out. If you are in pain, you cannot heal.
- If you are nauseous, ask your doctor for medications to help, and take those medications at the very first sign of nausea.

### Watch for patterns:

Many women experience a pattern of side effects as they move through each round of chemo. Keep a daily journal of how you are feeling - physically and mentally. If you can determine a pattern of when you feel side effects, then you will be able to anticipate and deal with them. Here are a few tips.

- Constipation and Diarrhea - Talk to your doctor about incorporating a stool softener, laxative, or anti-diarrheal medicine into your daily routine. A simple stool softener or anti-diarrheal pill once a day can make all the difference.
- Fatigue - Keep track of your lowest days and plan to rest as much as possible. Do not push yourself. Your body is fighting a battle and it needs rest.
- Feeling good days - You WILL have days when you feel good, typically right before your next treatment. Use these days for housecleaning, errand running and preparing for your next round of chemotherapy.
- Depression - Chemotherapy can affect brain chemistry. It's a smart move to talk to your doctor about an anti-depressant or anti-anxiety medicine and start it sooner rather than later in your treatment cycle.
- Bad days - If you notice days during your treatment cycle that are worse than others are (emotionally and/or physically), ask someone to stay with you on those days to help.
- You might notice that regular eating utensils taste awful and leave a metallic taste in your mouth. Using plastic utensils helps.
- Welcome the assistance from family, friends, neighbors and professionals. You do NOT get extra points for toughing it out. People want to help but do not know how to help. Give them an opportunity to show you that they care. Ask for help.
- Attend a support group. You will learn so many tips for combating side effects, managing treatment and coping.

## Clinical Trials

Many people think clinical trials, research studies that follow a predefined set of procedures, are only for those whose treatments have failed. However, a woman is eligible to participate in a clinical trial at any point; before, during or after treatment. Clinical trials can often provide the latest and most innovative medicine that experts think might help improve an individual's cancer outcome. To learn more, go to <https://clinicaltrials.gov/>

## Questions to ask your doctor about Clinical Trials

If you are thinking about taking part in a clinical trial, or your doctor offers you a trial, the National Cancer Institute suggest a patient might ask the following questions:

- What is the purpose of the trial?
- Why do the researchers believe that the treatment being studied may be better than the one being used now?
- Why may it not be better?
- How long will I be in the trial?
- What kinds of tests and treatments are involved?
- How will the doctor know if the treatment is working?
- How will I be told about the trial's results?
- How long do I have to make up my mind about joining this trial?
- Who can I speak with about questions I have during and after the trial?
- Who will be in charge of my care?
- Is there someone I can talk to who has been in the trial?

- **Risks and Benefits**

- What are the possible side effects or risks of the new treatment?
- What are possible benefits?
- How do the possible risks and benefits of this trial compare to those of the standard treatment?

- **Comparing Choices**

- What are my other treatment choices, including standard treatments?
- How does the treatment I would receive in this trial compare with the other treatment choices?
- What will happen to my cancer without treatment?

## Finding Support

Going through a diagnosis of ovarian cancer is difficult, but it can help to know that you are not the only one going through the experience. “While not everyone wants or needs support beyond that offered by family and friends, you may find it helpful to turn to others outside your immediate circle. A support group can help you cope better and feel less isolated as you make connections with others facing similar challenges. A support group shouldn’t replace your standard medical care, but it can be a valuable resource to help you cope. Support groups are not the same as group therapy sessions. Group therapy is a formal type of mental health treatment that brings together several people with similar conditions under the guidance of a trained mental health provider.

Members of a support group usually share their personal experiences and offer one another emotional comfort and moral support. They may also offer practical advice and tips to help you cope with your situation. Benefits of participating in support groups may include:

- Feeling less lonely, isolated or judged
- Gaining a sense of empowerment and control
- Improving your coping skills and sense of adjustment
- Talking openly and honestly about your feelings
- Reducing distress, depression or anxiety --Developing a clearer understanding of what to expect with your situation
- Getting practical advice or information about treatment options
- Comparing notes about resources, such as doctors and alternative options.

## Women and Infants

**GYN Cancer Support Group** - Meets the first aThursday of every month, 5 to 6:30 p.m., 668 Eddy St., third floor conference room, Providence. Facilitated by Diane Thompson, MSW, LICSW, (401) 274-1122, ext. 47202, dthompson@wihri.org.

**Caregivers Support Group** - Meets the fourth Monday of every month, 6 to 7:30 p.m., 668 Eddy St, second floor conference room, Providence. Facilitated by Dana D’Alessandro Haseotes, MSW, LICSW, MPH, (401) 274-1122, ext. 47111, dhaseotes@wihri.org.

**Transition to Survivorship Educational/Support Group** - For survivors transitioning from active treatment to post treatment. Please call for dates,times, and location. Facilitated by: Dana D’Alessandro Haseotes, MSW, LICSW, MPH, (401) 274-1122, ext. 47111, dhaseotes@wihri.org.

## Dana-Farber Cancer Institute

Gynecologic Cancer Support Group this support group meet sthe third Monday of each month, from 5 to 6:30 pm. For mor information about attending , please cotact Bebe Nixon, MSW, LICSW: Bebe\_Nixon@dfci.harvard.edu.

## Online Support

Ovarian Cancer Research Fund Alliance's Inspire Ovarian Cancer Online Support Community The Inspire website network creates community for anyone who faces health issues, and provides a place where patients, families, friends and caregivers can ask questions and connect with one another.

<https://ocrahope.org/patients/information-on-covid-19-for-ovarian-cancer-patients/staying-connected-online-support-group/>

### CancerCare

CancerCare® offers a 15-week online support group for women diagnosed with ovarian cancer who are currently receiving treatment. In this group led by an oncology social worker, patients give support to each other and share resources and information. To join this group, please complete the online registration process. After joining this password-protected group, you can read and post messages 24 hours a day, 7 days a week.

[www.cancercare.org/support\\_groups/51-ovarian\\_cancer\\_patient\\_support\\_group](http://www.cancercare.org/support_groups/51-ovarian_cancer_patient_support_group)

### Imerman Angels

Imerman Angels provides personalized connections that enable 1-on-1 support among cancer fighters, survivors and caregivers. Through our unique matching process, Imerman Angels partners anyone seeking cancer support with someone just like you - a "Mentor Angel."

<http://imermanangels.org>

### Cancer Support Community

Provides emotional and educational services for all people affected by cancer.

[www.cancersupportcommunity.org/online-support](http://www.cancersupportcommunity.org/online-support)

### Smart Patients - Ovarian Cancer Community

The Smart Patients Ovarian Cancer community is an online support group where members dealing with ovarian cancer share advice and support with other patients and caregivers.

[www.smartpatients.com/communities/ovarian-cancer](http://www.smartpatients.com/communities/ovarian-cancer)

### MyLifeLine.org

MyLifeLine.org is a 501(c)3 nonprofit organization that encourages cancer patients and caregivers to create free, customized websites. The mission is to empower patients to build an online support community of family and friends to foster connection, inspiration, and healing.

[www.mylifeline.org](http://www.mylifeline.org)

### HysterSisters

Woman to woman hysterectomy support

<http://www.hystersisters.com>

## Young Survivors

**Young Women's Support Group** - For patients under the age of 40 with all types of cancer. Meets the second Tuesday of every month, 5:30 to 7 p.m., 668 Eddy St., third floor conference room, Providence. Facilitated by Dana D'Alessandro Haseotes, MSW, LICSW, MPH, (401) 274-1122, ext. 47111, dhaseotes@wihri.org.

## Young Empowered Survivors - (YES)

Young Empowered Survivors is primarily an online resource. To join: please send an email to us at [youngempoweredurvivors@gmail.com](mailto:youngempoweredurvivors@gmail.com). List your type of cancer, age at diagnosis and where you live.

## Stupid Cancer

Comprehensively addressing young adult cancer through advocacy, research, support, outreach, awareness, mobile health, and social media, Stupid Cancer proudly supports a global network of patients, survivors, caregivers, providers, and advocates.  
<http://stupidcancer.org>

## Telephone Support

### Support Connection, Inc.

is a not-for-profit organization that provides emotional, social and educational support to women, their families and friends affected by breast and ovarian cancer. Although our office is in Yorktown Heights, NY, we help people all over the country via our toll-free services.

<http://supportconnection.org> or 914.962.6402 or 1.800.532.4290

### Share: Self Help for Women with Breast or Ovarian Cancer

We can give you support . . . based on our experience as survivors.

[www.sharecancersupport.org](http://www.sharecancersupport.org) or 866.537.4273 / 844.275.7427

### Cancer Support Community (CSC) - Cancer Support Helpline

“Whether you are newly diagnosed with cancer, a long-time cancer survivor or caring for someone with cancer, CSC’s TOLL-FREE Cancer Support Helpline is open weekdays 9 am- 8 pm ET.

[www.cancersupportcommunity.org](http://www.cancersupportcommunity.org) or 1.888.793.9355

**Woman to Woman (W2W)** is a national program of the Ovarian Cancer Research Alliance, available in more than 40 hospital-based and community programs nationwide. W2W offers women with gynecologic cancers the opportunity to meet with a trained mentor volunteer. Volunteer mentors offer women comfort, help and advice by sharing the wisdom, experiences and insight of someone who has walked in their shoes.

**Find out more:** If you are a survivor of a gynecologic cancer and would like to become a volunteer mentor or if you are diagnosed with a gynecologic cancer and would like to talk with a volunteer mentor, please contact Susan Garland, LICSW at 401-606-2044.

## **Additional Support**

### **Oncology Social Workers**

Most medical and infusion centers have a licensed clinical social worker (LCSW) on staff. These are professionals skilled in the issues that arise in the course of a cancer diagnosis, both for the patient and caregiver. They are a wealth of information and can be of great assistance. Check at your doctor's office for more information.

### **Patient Navigators**

American Cancer Society Navigators act on behalf of those affected by cancer in every community to identify and obtain beneficial resources. Navigators offer free, confidential assistance to cancer patients and those who care for them. Navigators are trained to listen to you, learn your needs and put together a plan of action that is tailor-made just for you. Your American Cancer Society Navigator can tell you more about our survivorship initiatives that include supportive care services such as Reach To Recovery, Look Good - Feel Better and I Can Cope. The American Cancer Society also offers services to reduce barriers to treatment through its at Home for medical equipment needs), transportation and pain management education programs. In addition to these services, an American Cancer Society Navigator can provide you with a full array of community referrals tailored to your individual needs. call 1-800-ACS-2345 and ask for a Navigator in your community.

### **American Cancer Society Resource Centers for Cancer Patients and Their Families**

A resource center, in partnership with a cancer care center, offers patients, families, and the public current information about cancer, American Cancer Society programs, and local community resources. Volunteers assist visitors in obtaining information about prevention/detection, treatment guidelines, and support groups. Those using the resource center will be able to listen to, or read prerecorded personal stories and discussions among survivors and caregivers via the Cancer Survivors' Network. Wigs are available at some centers for those without insurance.

## Financial Assistance

Understanding Health Insurance – Get information about private and government insurance plans, as well as other possible sources of financial help for people with cancer.

<https://www.cancer.org/treatment/finding-and-paying-for-treatment/understanding-health-insurance.html?sitearea=&level=1>

## Patient Advocate Foundation

Patient Advocate Foundation's Financial Aid Fund Division may offer a variety of Financial Aid Fund options available at any given time, with a current listing that can be found at [www.patientadvocate.org/financialaid](http://www.patientadvocate.org/financialaid) or by calling 1-855- 824-7941

## Cancer Care

Offers limited financial assistance for cancer-related costs such as transportation and child care, and oncology social workers can help you find

[resources.https://www.cancercare.org/financialresources](https://www.cancercare.org/financialresources)

## The Fly Foundation

Provides support to young adults diagnosed with cancer, aged 19-39, who are US citizens and residents of Massachusetts or Rhode Island. Funds may reimburse recipients for co-insurance, co-pays, and living expenses, including rent/mortgage payment and utilities, during treatment. <http://theflyfoundation.org>

## Giving Hope Fund

The "Giving Hope Fund" allows young adults currently battling cancer, as well as those who have been in remission for up to 5 years after their treatment, the opportunity to help pay for necessities they encounter in everyday life.

<http://www.hope4yawc.org/giving-hope-fund/>

## Heaps of Hope

Heaps of Hope reaches out to some of the most vulnerable in our society: women with a cancer diagnosis. A serious illness puts a great deal of stress on every aspect of a person's life, including their financial situation. <http://heapsofhope.org>

## The Sam Fund

Provides support to young adults who are struggling financially because of cancer. Through direct financial assistance and free online support and education, we help young adults survive and move forward with their lives after cancer. <http://www.thesamfund.org>



# Medical Cost Assistance

## Patient Access Network

“To help underinsured people with life-threatening, chronic and rare diseases get the medications and treatment they need by paying for their out-of-pocket costs and advocating for improved access and affordability. We envision a nation in which everyone can get the health care they need.” [www.panfoundation.org/ovarian-cancer](http://www.panfoundation.org/ovarian-cancer) or **866-316-7263**

## NeedyMeds

NeedyMeds is a national non-profit organization that maintains a website of free information on programs that help people who can't afford medications and healthcare costs. [www.needymeds.org](http://www.needymeds.org)

## The Lois Merrill Foundation

Provides carcinoid and other rare cancer patients with assistance in the payment of medical expenses. This grant is based on financial need and the average awards is less than \$2,000. <http://www.thelmf.com>

## Good Days

Exists to improve the health and quality of life of patients with chronic disease, cancer, or other life-altering conditions. We help patients suffering from chronic medical conditions who have limited financial means get access to the medications they need. Our program helps qualified patients pay their insurance co-pays so they can get immediate access to prescription medications that will give them relief from pain and suffering. [www.gooddaysfromcdf.org](http://www.gooddaysfromcdf.org) or **877-968-7233**

## Patient Advocate Foundation – Co-Pay Relief Fund

“Provides financial assistance to financially and medically qualified patients, including those insured through federally administered health plans such as Medicare, for co-payments, co-insurance and deductibles required by a patient’s insurer for pharmaceutical treatments and/or prescription medications prescribed to treat and/or manage his/her disease.”

[www.copays.org/diseases/ovarian-cancer](http://www.copays.org/diseases/ovarian-cancer) or **1.866-512-3861**

## Partnership for Prescription Assistance

“The Partnership for Prescription Assistance helps qualifying patients without prescription drug coverage get the medicines they need through the program that is right for them. Many will get their medications free or nearly free.” [www.pparx.org/en](http://www.pparx.org/en) or **1-888-477-2669**.

# Transportation, Travel and Lodging Support

## CancerCare

Provides limited financial assistance for treatment-related transportation to people affected by cancer.

[http://www.cancercare.org/publications/303-transportation\\_resources](http://www.cancercare.org/publications/303-transportation_resources)

Provides transportation to and from treatment for people who have cancer but do not have a ride or are unable to drive themselves. Volunteer drivers donate their time and the use of their cars. Patients must have a cancer diagnosis and be travelling for a cancer-related medical appointment. A 4 business day advance notice is required; not including the date transportation is needed.”

[www.cancer.org/treatment/supportprogramsservices/road-to-recovery](http://www.cancer.org/treatment/supportprogramsservices/road-to-recovery)

## National Patient Travel Center

Provides referrals and ‘how to get there’ assistance for any patient needing to travel to a distant, specialized medical facility for evaluation, diagnosis or treatment.

[www.patienttravel.org](http://www.patienttravel.org)

## Corporate Angel Network

Corporate Angel Network helps cancer patients access the best possible treatment by arranging free travel to treatment across the country using empty seats on corporate jets.

<http://corpangelnetwork.org>

## Air Charity Network

Serves all 50 states and provides free flights to people in need of medical treatment.

[www.aircharitynetwork.org](http://www.aircharitynetwork.org)

## Angel Wheels to Healing

Provides non-emergency, long distance ground transportation to financially disadvantaged patients for treatment. [www.angelwheels.org](http://www.angelwheels.org)

## Good Days

Helps patients with chronic medical conditions who have limited financial means with transportation. [www.mygooddays.org](http://www.mygooddays.org)

## American Cancer Society (ACS) Patient Lodging Program

In a cooperative effort with hotels across the country, provides overnight accommodations to cancer patients who must travel for outpatient treatment and need assistance with lodging. [www.cancer.org/treatment/supportprogramsservices/patient-lodging/index](http://www.cancer.org/treatment/supportprogramsservices/patient-lodging/index)

# Transportation, Travel and Lodging Support

## Joe's House

A non-profit organization providing an online nation-wide list of places to stay to assist cancer patients and their families find lodging near treatment centers. Joe's House lists various types of lodging throughout the United States that are near to hospitals and treatment centers." [www.joeshouse.org/](http://www.joeshouse.org/)

## National Association of Hospital Hospitality Houses, Inc. (NAHHH)

A nationwide professional association of nearly 200 unique, nonprofit organizations that provide lodging and support services to patients, families and their loved ones who are receiving medical treatment far from their home communities. [www.nahhh.org](http://www.nahhh.org)

## Social Security Administration

With a diagnosis of ovarian cancer, you are likely eligible for Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI). Contact the U.S. Social Security Administration for more information and **ask about Compassionate Allowance\***

\*The Compassionate Allowances (CAL) initiative is a way to expedite the processing of SSDI and SSI disability claims for applicants whose medical conditions are so severe that their conditions obviously meet Social Security's definition of disability. It is not a separate program from SSA's two disability programs, SSDI and SSI..

[www.ssa.gov/pgm/disability.htm](http://www.ssa.gov/pgm/disability.htm) [www.ssa.gov/pgm/ssi.htm](http://www.ssa.gov/pgm/ssi.htm) or **Hotline: 800-772-1213**

Centers For Medicare & Medicaid Services  
[www.medicare.gov](http://www.medicare.gov) or **800-Medicare**

## Medicare Rights Center

A national, nonprofit consumer service organization that works to ensure access to affordable health care for older adults and people with disabilities. If you are under 65 years of age with an ovarian cancer diagnosis, you still may be eligible for Medicare based on disability after certain requirements are met. [www.medicarerights.org](http://www.medicarerights.org) or **Hotline 800-333-4114**

# Support for Caregivers

## CancerCare® - 12-week Telephone Group for Caregivers

“CancerCare® is a national nonprofit organization that provides free, professional support services to anyone affected by cancer. CancerCare® offers a 12-week telephone group for people who have a loved one diagnosed with cancer.”

[www.cancer.org/support\\_groups](http://www.cancer.org/support_groups)

## Frankly Speaking About Cancer: Ten Tips for Caregivers booklet

“A cancer caregiver is anyone who provides physical, emotional, financial, spiritual or logistical support to a loved one with cancer.”

[www.cancersupportcommunity.org/sites/default/files/uploads/living-with-cancer/topics/resource/fsac\\_ten\\_tips\\_for\\_caregivers.pdf](http://www.cancersupportcommunity.org/sites/default/files/uploads/living-with-cancer/topics/resource/fsac_ten_tips_for_caregivers.pdf)

## Caring for the Caregiver - Cancer Survival Toolbox® Special Topics

“Caring for the Caregiver was developed specifically to provide resources and support for cancer caregivers to help them address the issues they face on an ongoing basis.”

[www.canceradvocacy.org/resources/cancer-survival-toolbox/special-topics/caring-for-the-caregiver/](http://www.canceradvocacy.org/resources/cancer-survival-toolbox/special-topics/caring-for-the-caregiver/)

## Cancer.net – Caring for a Loved One

Information on topics including: “...How Caregivers Can Take Care of Themselves, Exploring New Caregiver Options, Sharing Responsibilities, Caregiving at the Hospital, Providing Care at Home, Long-Distance Caregiving, Parenting While Caring for a Parent

[www.cancer.net/coping-with-cancer/caring-loved-one](http://www.cancer.net/coping-with-cancer/caring-loved-one)

## NCI Guidebook for People Helping Someone with Cancer

“This booklet is for you if you’re helping your loved one get through cancer treatment. You are a ‘caregiver.’ You may not think of yourself as a caregiver. You may see what you're doing as something natural (taking care of someone you love). There are different types of caregivers. Some are family members, while others are friends. Every situation is different. So there are different ways to give care. There isn't one way that works best.” There are additional resources listed in this useful booklet. [www.cancer.gov/publications/patient-education/when-someone-you-love-is-treated.pdf](http://www.cancer.gov/publications/patient-education/when-someone-you-love-is-treated.pdf)

## Next Step in Care

Next Step in Care provides easy-to-use guides to help family caregivers and health care providers work closely together to plan and implement safe and smooth transitions for chronically or seriously ill patients. <http://www.nextstepincare.org>

# Support for Caregivers

## U.S. Food and Drug Administration, Office of Women's Health Tips for Caregivers

FDA's Tips for Caregivers website provides tools to help caregivers manage the care of their loved ones. The website provides tips for caregivers of older adults, young children, teens and people with special needs. The website also highlights 7 tips for all caregivers to know. FDA Office of Women's Health also provides information on women and clinical trials.

[fda.gov/womeninclinicaltrials](http://fda.gov/womeninclinicaltrials)

## Caregiver Action Network

Resources from the Caregiver Action Network, including a Peer Forum, a Story Sharing platform, the Family Caregiver Tool Box and more. <http://www.caregiveraction.org> CAN also provides support for rare disease caregivers at <http://www.rarecaregivers.org>

## Help For Cancer Caregivers

"Help for Cancer Caregivers is a unique collaboration of organizations with a shared goal of improving the health and well-being of the people who care for people with cancer."

[www.HelpForCancerCaregivers.org](http://www.HelpForCancerCaregivers.org)

## Well Spouse Association

Supports 'well' individuals caring for a spouse or partner with a chronic illness or disability.

[www.wellspouse.org](http://www.wellspouse.org)

## Lotsa Helping Hands

Is a free service that brings together caregivers and volunteers through online communities that help organize daily life during times of medical crisis or caregiver exhaustion.

[www.lotsahelpinghands.com](http://www.lotsahelpinghands.com)

## CaringBridge

Helps you create a free personal website to quickly share updates about your own or someone else's health journey. [www.caringbridge.org](http://www.caringbridge.org)

## A Cancer Survivorship Plan

### LIVESTRONG® Survivorship Center of Excellence at Dana Farber Cancer Institute

“The Dana Farber survivorship program is one of seven LIVESTRONG® Survivorship Centers of Excellence supported by the LIVESTRONG® Foundation. We offer resources, support, and information to cancer survivors. Our comprehensive cancer survivorship program includes; Support groups and educational classes,; Ongoing cancer survivorship needs assessment,;Clinical programs for cancer survivors,;Cancer survivor research and distribution.”

<http://www.dana-farber.org/Adult-Care/Treatment-and-Support/Treatment-Centers-and-Clinical-Services/Adult-Survivorship-Program.aspx>

## Cancer Survivorship Care Plans

“A treatment summary and survivorship care plan is a report of your medical history created for both you and your health care providers to help ensure you receive appropriate follow-up care. The plan includes a recap of all treatments you’ve received, as well as follow-up care instructions and important information needed to monitor for late- and long-term effects of your cancer treatment. You and your health care team are the best source for creating treatment summaries and survivorship care plans. To help you start the discussion, check out these tools:”

**LIVESTRONG® Care Plan:** <http://livestrongcareplan.org> ASCO Cancer Treatment Summaries: [www.cancer.net/survivorship/asco-cancer-treatment-summaries](http://www.cancer.net/survivorship/asco-cancer-treatment-summaries) Journey

**Forward Survivorship Care Plan:**

<http://www.journeyforward.org/what-is-cancer-survivorship-care-planning>

## ASCO Answers: Cancer Survivorship Booklet

“As you finish cancer treatment, you might be wondering: What happens next? The answer is different for every person. Some people return to the lives they were leading before their diagnosis, while the lives of others are significantly changed by their cancer experience. The challenge for every survivor is figuring out how to return to everyday life while adjusting to the effects of the disease and its treatment.” See this booklet from the American Society of Clinical Oncology at Cancer.net. for more information.

[www.cancer.net/sites/cancer.net/files/cancer\\_survivorship.pdf](http://www.cancer.net/sites/cancer.net/files/cancer_survivorship.pdf)

## NCCS Cancer Survivor Toolbox® - Living Beyond Cancer

“Surviving cancer is more complicated than simply being sick or well, having cancer or being cancer free. Instead, it is a continual process that is constantly changing. There may be times when the joy you feel about survival far outweighs any anxieties you may have. Then, there will be times when your fears and uncertainties seem to take over your life, and you wonder if you will ever feel normal again. This program will introduce you to skills to help you adapt to your life after cancer. The goal is to help you, a cancer survivor, be as healthy as possible within your personal circumstances.” The Toolbox program is available for listening online in both English and Spanish.

[www.canceradvocacy.org/resources/cancer-survival-toolbox/special-topics/living-beyond-cancer/](http://www.canceradvocacy.org/resources/cancer-survival-toolbox/special-topics/living-beyond-cancer/)

# A Cancer Survivorship Plan

## Nutrition and Physical Activity Guidelines for Cancer Survivors - American Cancer Society

[www.cancer.org/healthy/informationforhealthcareprofessionals/acsguidelinesnupaguidelinesforcancersurvivors](http://www.cancer.org/healthy/informationforhealthcareprofessionals/acsguidelinesnupaguidelinesforcancersurvivors)

This guide is a tool to arm you with the information needed to help you through your journey. The information may seem overwhelming at first but know that you are not alone. You will get through this with the help of your doctors, healthcare team, family, friends and all of us at the Rhode Island Ovarian Cancer Alliance.

A special thank you to the Colorado Ovarian Cancer National Alliance for allowing us to use their resource guide as a draft.

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