



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.



Survivorship

What Does “Survivorship” Mean?



“This [NCI] booklet uses the term “cancer survivor” to include anyone who has been diagnosed with cancer, from the time of diagnosis through the rest of his or her life. Family members, friends, and caregivers are also part of the survivorship experience. You may not like the word, or you may feel that it does not apply to you, but the word “survivor” helps many people think about embracing their lives beyond their illness.”

www.cancer.gov/publications/patient-education/life-after-treatment.pdf

National Coalition of Cancer Survivorship

“In 1986, the founders of NCCS [National Coalition of Cancer Survivorship] saw a need for language that truly told the story of life after a cancer diagnosis. At the time, there were a growing number of people living beyond their cancer diagnosis and treatment. Many of them were experiencing an array of health issues related to their treatment, as well as late and long-term effects. They also faced psychological, financial, emotional, spiritual, and social challenges. The phrase “cancer survivorship” was created to describe this broad experience on the cancer continuum — living with, through, and beyond a cancer diagnosis.... Many continue to struggle with how to define “survivor,” or whether to use it at all. We recognize that the term “cancer survivor” may be seen differently by people based on their own experiences.”

www.canceradvocacy.org/news/defining-cancer-survivorship/

Once Treatment Ends...



While it is normal to look forward to the day when chemotherapy ends and life goes back to normal, it can often be a bumpy time of transition and readjustment. During surgery and chemo when the focus is on survival, your healthcare team, friends and family are generally right there for you. Once your treatment ends, however, the focus dissipates while the trauma and grief of the experience may come forward to finally be processed. This is a phenomenon now understood by cancer experts, who suggest developing a “Survivorship Care Plan” that includes pro-active ways to move forward after treatment.

ting back to normal” as it is finding out what’s normal for you now. People often say that life has new meaning or that they look at things differently.”

www.cancer.gov/about-cancer/coping/survivorship/new-normal

A New Normal



“The end of cancer treatment is often a time to rejoice. Most likely you’re relieved to be finished with the demands of treatment. You may be ready to put the experience behind you and have life return to the way it used to be. Yet at the same time, you may feel sad and worried. It can take time to recover. And it’s very common to be thinking about whether the cancer will come back and what happens now. Often this time is called adjusting to a “new normal.” You will have many different feelings during this time. One of the hardest things after treatment is not knowing what happens next. Those who have gone through cancer treatment describe the first few months as a time of change. It’s not so much “get-

“Chemo Brain”



“For years people with cancer have worried about, joked about, and been frustrated by the mental cloudiness they sometimes notice before, during, and after cancer treatment. Even though its exact cause isn’t always known, and it can happen at any time during cancer, this mental fog is commonly called chemo brain. Patients have been aware of this problem for some time, but only recently have studies been done that could help to explain it.”

www.cancer.org/treatment/treatmentsandsideeffects/physicalsideeffects/chemotherapyeffects/chemo-brain

“Though patients and survivors often complain of chemo brain during and after treatment for cancer, a growing body of research shows that there are multiple causes behind the cognitive decline many survivors experience.”

www.curetoday.com/articles/more-than-chemo-brain-several-factors-contribute-to-cognitive-decline-after-cancer?p=1

A Cancer Survivorship Plan

LIVESTRONG® Survivorship Center of Excellence at University of Colorado Cancer Centers

University of Colorado Cancer Center, UCHHealth locations at St. Mary's Regional Cancer Center in Grand Junction and St. Mary-Corwin Medical Center in Pueblo—and across the Rocky Mountain region.

720-848-0316 uch-survivorship@uch.edu

“The University of Colorado survivorship program is one of seven LIVESTRONG® Survivorship Centers of Excellence supported by the LIVESTRONG® Foundation. Through UCHHealth, the CU Cancer Center, and our extensive network of partnerships, we offer resources, support, and information to cancer survivors in Colorado—including our community-based centers at St. Mary's Regional Cancer Center in Grand Junction and St. Mary-Corwin Medical Center in Pueblo—and across the Rocky Mountain region. 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.”

www.uchealth.org/Pages/Services/Cancer-Care/Support-and-Education/Survivorship-Clinics.aspx

The “What Is Next? (WIN)” Program at University of Colorado Cancer Center

UCH Stapleton Clinic (AF Williams), 3055 Roslyn St., Suite 100. Denver, CO 80238.

720.848.0300, 720-848-0316 uch-survivorship@uch.edu

“If you've recently completed cancer treatment and you're wondering what is next, the WIN program at UCHHealth can help you find answers. Through WIN, you can join one of our groups to participate in a series of up to six clinic visits led by health care professionals with cancer-specific clinical experience. Although most insurance plans cover this program, each session requires a co-pay. To gain the full benefit, you'll want to commit to attending all sessions. WIN clinic visits are designed to: Help you identify your cancer survivorship health care needs; Learn about symptom management; Receive the most recent information about how to keep yourself healthy; Develop a personalized wellness plan; Assist you in creating a partnership with your medical team; Link you to appropriate resources and referrals; Help you understand how treatment summary and care documents can be useful for your future health care needs; UCHHealth specialty providers who lead our WIN clinic visits include: Physicians, Physical therapists, Dietitians, Exercise specialists, Health psychologists.”

www.uchealth.org/Pages/Services/Cancer-Care/Support-and-Education/Survivorship-Clinics.aspx

- click on Cancer Survivorship Clinical Programs link.

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:”

www.uchealth.org/Pages/Services/Cancer-Care/Support-and-Education/Survivorship-Clinics.aspx

LIVESTRONG® Care Plan:

<http://livestrongcareplan.org/>

ASCO Cancer Treatment Summaries:

www.cancer.net/survivorship/asco-cancer-treatment-summaries

Journey Forward Survivorship Care Plan:

www.journeyforward.org/what-is-cancer-survivorship-care-planning

NATIONAL

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/

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

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

www.cancer.org/healthy/informationforhealth-careprofessionals/acsguidelines/nupaguidelinesforcancersurvivors/

In Case of Recurrence



One of the realities of ovarian cancer is the concern of recurrence. While it is best not to live with continual anxiety about the possibility, it is wise to have a plan in case it happens. If ovarian cancer does recur, it can be helpful to have a “molecular profile” of the tumor done in order to see what mutations are present in the cancer (this is in addition to the BRCA genetic testing that may have been done to determine family inheritance). This is also a time to consider clinical trials, before the use of more chemo reduces the opportunity to join a study. See more about Genetic Considerations and Clinical Trials on pages 19-26.

“Learning that you have recurrent ovarian cancer brings on many new fears, concerns and questions. You may feel similar to how you felt when you were newly diagnosed, however, some women say they feel more uncertain following a recurrence... The National Ovarian Cancer Coalition hopes this booklet will help you to make informed decisions about your treatment for recurrence and be proactive in managing your health.”

www.ovariancancertogether.org/documents/resourceguiderecurrentovariancancer.pdf

Tumor Blueprint / Molecular Profile For Recurrent Ovarian Cancer The Clarity Foundation

4365 Executive Drive, Suite 1500, San Diego, CA 92121
858.657.0282 info@clarityfoundation.org

“The Clarity Foundation strives to help ovarian cancer patients and their physicians make better-informed treatment decisions based on molecular profiling of tumors. Our goal is to help women with recurrent ovarian cancer live longer, healthier lives... The Clarity Foundation provides you with a personalized Tumor Blueprint designed to help inform therapy selection. We provide insights based on key features of your tumor at the molecular level. The Tumor Blueprint is generated by measuring a panel of protein biomarkers and detecting genetic changes in your tumor. Your Tumor Blueprint interpretative report suggests drug treatments that match and therefore may be more likely to be effective for you. Some of those drugs may be available through clinical trials for which you may be eligible. Cost of the Tumor Blueprint: As a non-profit organization, Clarity Foundation provides its patient support services **free of charge**. Our services include molecular testing coordination, reporting and interpretation of results, and identification of clinical trials for which you may be eligible. The cost of the molecular testing will vary depending on your insurance. Feel free to contact Clarity at 858.657.0282 with questions or concerns.”

www.clarityfoundation.org/find-treatment-options/get-a-tumor-blueprint/

Charles W. Nutting, D.O., FSIR – Liver specialist
RIA Endovascular 8200 E Belleview Ave, Suite 600E,

Greenwood Village, CO 80111 720.493.3406

“Dr. Nutting is a board-certified, fellowship-trained interventional radiologist specializing in performing minimally invasive image-guided procedures to treat liver cancer and vein disorders... World Renown for Interventional Treatment of Liver Cancer: Charles Nutting offers leading-edge procedures including chemoembolization, radiofrequency ablation and selective internal radiation therapy (SIRT). When not in the office, he treats endovascular disease, vein disorders and cancer in local and regional hospitals throughout the Rocky Mountain region. He is Chief of Interventional Radiology at Sky Ridge Medical Center. Dr. Nutting was the first physician in the United States to do liver radioembolization with Sir-Sphere®. He has since performed more than 900 radioembolization procedures, and teaches this SIRT procedure using Y90 internal radiation beads nationwide... “Best Doctor” designation: Charles Nutting has been recognized as a “Best Doctor” in the Denver Business Journal’s August 7-13, 2015 edition.”

www.riaendovascular.com/our-physicians/interventional-radiologists/nutting/

Bruckner Oncology – Traditional and Alternative Cancer Treatment

2330 Eastchester Road, Bronx, NY 10469 718.732.4050

“Traditional Cancer Treatment: Traditional chemotherapy treatment uses chemical drugs in an effort to stop cancer cells from growing and hopefully eradicate the cancer. For many of our patients, chemotherapy represents an effective way to treat, and hopefully, eliminate cancer. At Bruckner Oncology, we provide a specific treatment plan and schedule to each patient comprised of agreed upon cancer fighting drugs to work toward fighting the cancer, as well as seeing the treatment through to support the entire process.

Alternative Cancer Treatment: A specialized, innovative treatment methodology for cancers that respond poorly to traditional approaches or have failed conventional therapy. Understanding Drug Resistance: Unfortunately, not all tumors are receptive to traditional chemotherapeutic regimens... Bruckner Oncology is a pioneer in this area, leading the way in research and experience to allow physicians worldwide to better understand the what, why and how of chemotherapeutic drug combinations to enable the best arsenal of treatment options in the fight against all types of cancers.”

www.bruckneroncology.com/

DirectLabs.com

“DirectLabs.com provides direct access laboratory testing for those who want to take charge of their own health and personally monitor their own wellness. We assist in the prevention or early detection of disease by providing discounted, high quality online blood and laboratory testing services directly and confidentially to consumers.”

www.directlabs.com

Palliative Care



★ Palliative care is not the same as hospice. It is care aimed at relieving symptoms of surgery & chemo and can be used from the very beginning of a cancer diagnosis. Palliative care can also be supportive for the caregiver, as a team is provided to address many aspects of the experience. Check with your insurance provider first to see if they cover the cost of a palliative care team.

What Is Palliative Care?

“Palliative Care (pronounced PAL-lee-uh-tiv) is specialized medical care for people with serious illnesses. It focuses on providing patients with relief from the symptoms, pain, and stress of a serious illness—whatever the diagnosis. The goal is to improve quality of life for both the patient and the family. Palliative care is appropriate at any age and at any stage in a serious illness. Unlike hospice care, palliative care can be provided together with curative treatment. It is especially appropriate for patients suffering from conditions like... cancer. Palliative care focuses on managing symptoms such as pain, shortness of breath, fatigue, constipation, nausea, loss of appetite, difficulty sleeping and depression. It also helps you gain the strength to carry on with daily life. It improves your ability to tolerate medical treatments. And it helps you have more control over your care by improving communication so that you can better understand your choices for treatment.

Palliative care is typically provided by a team including a physician, nurse, and other specialists who work with you, your family, and your other healthcare providers to provide an extra layer of support.... Defining features of a palliative care program, however, include:

- The affirmation of life and regard for dying as a normal process
- The intent to neither hasten nor postpone death
- Care throughout the continuum of illness in conjunction with curative therapies
- Availability of interventions early in the course of illness to assist with symptom management or advance care planning
- The use of an interdisciplinary team approach to address the comprehensive needs of patients and families including:
- An assessment and management of patient’s pain and other distressing symptoms
- Integration of the psychological and spiritual aspects of patient and family care
- Offering a support system to help patients live as fully as possible
- Offering a support system to help the family cope during the patient’s illness and in their bereavement.”

Life Quality Institute

61 Inverness Drive East, Suite 210 Englewood, CO 80112
“Our mission is simple ... by educating healthcare profes-

sionals and the public, Life Quality Institute advances the understanding and quality of palliative care.”

<http://lifequalityinstitute.org/about-palliative-care/what-is-palliative-care/>

GetPalliativeCare.org: Patient Perspectives Christine’s Palliative Care Story

“In this podcast, we hear from Christine Buehlmann, a California woman whose life changed dramatically after she was diagnosed with ovarian cancer and began receiving chemotherapy. Christine discusses how the physical and emotional symptoms of her disease and its treatment were hindering her quality of life, until she received palliative care.”

<https://getpalliativecare.org/whatis/disease-types/ovariancancer/>

Palliative Care Providers In Colorado

“A number of hospice organizations in Colorado offer palliative care services [at home] distinct from hospice services, not requiring a terminal diagnosis or six-month prognosis. These services vary in scope and frequency—who visits patients and how often. Some are primarily focused on helping patients and families discern goals and others primarily on symptom management. If you are interested in palliative home care, contact your local hospice agency and ask what services they provide and whether they might be covered by insurance or require payment. The following [list of] organizations may be able to assist you...” Another

<http://lifequalityinstitute.org/about-palliative-care/what-is-palliative-care/palliative-care-at-home/>

Another link to providers in Colorado:

<http://lifequalityinstitute.org/wp-content/uploads/2014/09/REVISED-Directory-of-Colorado-Palliative-Care-Providers-09-11-4.pdf>

Optio Health Services

Optio Palliative Care at Home 501 S. Cherry St., #700
Denver, CO 80246 303.321.2929 info@care4denver.org

“We offer physical and emotional support for our patients and their families facing serious disease. We are a consultative service that works directly with the physician team to ensure coordinated care. We are able to work with skilled homecare agencies, private duty providers, primary care or specialty care to ensure each patient’s goals are met.

Optio Palliative Care at Home focuses on:

- Acute pain and symptom management
- Emotional support for patient and family
- Advanced directives and goals of care discussions
- RN telephonic care management
- After hours phone support provided by our medical staff

We serve anyone with serious or advanced disease including those with cancer...”

www.optiohealth.org/OurServices/Pages/Optio-Palliative-Care-at-Home.aspx