LOW-GRADE SEROUS OVARIAN CANCER

RESOURCE GUIDE

Empowering individuals with knowledge, amplifying support, and helping ensure that no one navigating LGSOC feels alone.

This resource guide is dedicated to the individuals living with low-grade serous ovarian cancer (LGSOC), whose

STRENGTH, RESILIENCE, AND DETERMINATION

inspire deeper understanding of the disease, continued medical research and progress, and more resources.

Your voices and experiences are at the heart of this work.

FOREWORD

Being diagnosed with low-grade serous ovarian cancer (LGSOC) can feel overwhelming and bring up many different emotions.

Whether you are newly diagnosed, undergoing treatment, experiencing a recurrence, in surveillance, or living long-term with LGSOC, you may have many questions and uncertainties at different points during your journey. This guide was created to meet you where you are, offering accurate and reliable information, practical tools, and reassurance that you are not alone.

This resource brings together trusted educational materials, support services, and community connections from patient advocacy organizations. By compiling essential resources in one accessible place, this guide empowers individuals with LGSOC with knowledge, strengthens support, and helps ensure that no one navigating this disease feels alone.

ACKNOWLEDGEMENTS

Thank you to the advocacy organizations that developed the resources included in this guide.

They include:

- **SURVIVE. THRIVE. ADVOCATE. ADVANCE RESEARCH. (STAAR) Low-Grade Serous Ovarian Cancer Foundation**
- **Not These Ovaries**
- **National Ovarian Cancer Coalition (NOCC)**
- **Ovarcome**
- **Ovarian Cancer Research Alliance (OCRA)**
- **Sandy Rollman Ovarian Cancer Foundation**
- **SHARE Cancer Support**
- **Sharsheret**
- **Foundation for Women's Cancer**
- **Unite for HER**
- **World Ovarian Cancer Coalition (WOCC)***
- **Low-Grade Serous Ovarian Cancer Initiative (Ovarian Cancer Foundation New Zealand)***

* Global/Ex-US based organizations: please explore further for additional resources and support outside of the United States.

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INTRODUCTION

This resource guide supports individuals and their loved ones navigating LGSOC at every stage of the journey. It is intended to be a trusted companion offering information, tools, and support that you can return to whenever you have questions.

Each section focuses on a key aspect of living with LGSOC and begins with a brief overview to help orient you to the topic. Within each section, you will find tools and resources created by patient advocacy organizations that support individuals living with ovarian cancer, with a focus on LGSOC where available. These resources are intended to help you better understand this disease, prepare for conversations with your care team, support informed decision-making, and foster connection with the broader LGSOC community. While this guide will be updated annually, we recommend visiting patient advocacy groups' websites for more regular updates. More information on each of the groups can be found in the appendix.

This guide is not meant to be read from start to finish. Instead, you are encouraged to use the table of contents to select topics that reflect your current needs or experiences. You can return to different sections at different times, depending on where you are on your journey with LGSOC. No matter how you use the guide, it is here to help you feel informed, supported, and connected.

1 UNDERSTANDING YOUR LGSOC DIAGNOSIS

1A UNDERSTANDING LGSOC

1B IMPORTANCE OF AN ACCURATE DIAGNOSIS AND GENETIC TESTING

1C SYMPTOM TRACKING

1D YOUR INTEGRATED CARE TEAM

1A UNDERSTANDING LGSOC

LGSOC is a rare and distinct type of ovarian cancer. Although it is grouped under the broader term "ovarian cancer," LGSOC behaves differently from the more common high-grade serous ovarian cancer. These differences can affect how the disease grows, how it responds to treatment, and how it is managed over time.

LGSOC accounts for only a small percentage of ovarian cancer diagnoses, with estimates suggesting that approximately 1,000–2,000 people are diagnosed each year in the United States, and only several thousand individuals are currently living with the disease. Because it is uncommon, many people – including some healthcare providers – may be less familiar with it.

Although LGSOC is often slower-growing, it can still be serious and long-lasting. Many people experience the disease as a chronic condition that requires ongoing management. Studies have shown that recurrence is common and living with the uncertainty of if, or when, cancer may return is a significant emotional burden for many individuals.

Because LGSOC is uncommon and its symptoms such as bloating, pelvic or back pain, and changes in bowel habits can be vague or overlap with other conditions, receiving an accurate diagnosis often takes time. Some people are initially told they have a different type of ovarian cancer or another condition altogether, and delays of several years before a correct diagnosis are not unusual. The average individual waits almost 3 years until getting an accurate diagnosis, and this experience can feel frustrating, confusing, and isolating.

As you navigate the guide, you will learn more about genetic pathways and why understanding biological differences in tumor types is important to navigating care. LGSOC often does not respond to chemotherapy in the same way as other ovarian cancers.

Learning that your cancer is "different" can bring up a mix of emotions – uncertainty, fear, relief at finally having clarity, or all of the above. Review this resource to help you make sense of the basics at your own pace, so you feel more grounded as you move forward and explore questions about care, treatment options, and support.

The resources that follow explain LGSOC in clear language, define common terms, and offer perspectives from organizations and experts who focus on this disease.

Let's break down the terms within the disease:

LOW-GRADE refers to how the cancer cells look under a microscope. They tend to look more like normal cells and usually grow more slowly.

SEROUS describes the type of cells where the cancer begins. Which are found on the surface of the ovary or in nearby tissue.

RESOURCES TO EXPLORE:

Low-Grade Serous Ovarian Cancer: Your Complete Guide to Diagnosis, Treatment & Hope >
from Not These Ovaries

Comprehensive overview of LGSOC, including how it is diagnosed, how it differs from other ovarian cancers, and common treatment approaches. Designed to help patients and caregivers build a strong foundational understanding of LGSOC early in the journey.

LGSOC Overview >
from STAAR LGSOC Foundation

A patient-friendly overview of disease basics, treatment context, and lived-experience insights.

Low-Grade Serous Ovarian Cancer: What Should I Know >
from the Foundation for Women's Cancer

Concise, clinically grounded overview explaining LGSOC in clear language. Useful for understanding key features of the disease, common treatments, and questions to discuss with your care team.

Glossary of Ovarian Cancer Terms >
from the National Ovarian Cancer Coalition

Comprehensive glossary that defines medical and clinical terms related to ovarian cancer. Serves as a quick reference when reviewing educational materials, test results, and treatment information.

Low-Grade Serous Ovarian Cancer Research Catalogue >
from the Low-Grade Serous Ovarian Cancer Initiative

A research repository that provides detailed and specific information about LGSOC, including significant published studies, clinical guidelines, case studies, and review articles.

Questions to Ask Your Doctor: Low-Grade Serous Ovarian Cancer >
from the National Ovarian Cancer Coalition

Downloadable guide with practical questions to help you better understand your diagnosis and path forward. Includes questions about genetic and biomarker testing.

STARR LGSOC Patient Conference: Two Decades of Progress in the Understanding of LGSOC (Video) >
from STAAR LGSOC Foundation feat. Dr. David Gershenson

Expert-led discussion highlighting the past two decades of LGSOC research, lessons learned from observational studies and clinical trials, and future directions.

Navigating LGSOC Recurrence– Insights and Strategies >
from STAAR LGSOC Foundation feat. Dr. Lauren Cobb

Expert-led discussion on navigating recurrence in low-grade serous ovarian cancer, addressing common fears, and emphasizing the importance of living fully between monitoring intervals.

1B IMPORTANCE OF AN ACCURATE DIAGNOSIS AND GENETIC TESTING

Receiving a timely and accurate diagnosis of LGSOC is critical to treatment decisions but can be challenging because symptoms are often subtle and important genetic testing that can provide an accurate diagnosis is not always done.

In LGSOC, many tumors are influenced by changes in genes that affect how cancer cells grow and signal to one another. One of the most common of these is KRAS, a gene that acts like an on-off switch for cell growth. When KRAS is mutated, it can become stuck in the "on" position, contributing to cancer development and behavior.

Despite the role genes like KRAS can play in LGSOC, many people do not know the mutation status of their tumor, either because testing was not done, results were not clearly explained, or testing was not available at the time of diagnosis. Without this information, individuals may feel uncertain about their options or wonder whether important details about their cancer have been overlooked.

Learn more about tumor genetics, the role of expert pathology review, and why it may be worth revisiting these topics at various times throughout your care journey.

RESOURCES TO EXPLORE:

Understanding KRAS Mutation in Low-Grade Serous Ovarian Cancer >
from Not These Ovaries

Explains what KRAS mutations are and why they matter in LGSOC. Helps you understand biomarker testing and how specific mutations in your cancer may influence your treatment.

Genetic Mutations and Biomarkers in Ovarian Cancer >
from the National Ovarian Cancer Coalition

Animated educational resource explaining genetic mutations and biomarkers across ovarian cancer types. Useful if you are not familiar with molecular testing or personalized medicine.

Genetic Counseling Flyer >
from Ovarcome

Explains what genetic counseling is, who may benefit, and how it fits into ovarian cancer care. Helpful if you are considering or preparing for genetic testing.

RESOURCES TO EXPLORE *(CONTINUED)*:

OCRA's Free Genetic Testing Program >
from Ovarian Cancer Research Alliance

Provides access to free genetic testing and counseling for eligible individuals diagnosed with ovarian cancer. Aims to reduce financial barriers to essential genetic information.

STAAR LGSOC Patient Conference: Toward a Deeper Molecular Understanding of LGSOC (Video) >
from STAAR LGSOC Foundation

LGSOC expert covers the molecular pathogenesis of LGSOC, investigative approaches, and clinical implications of a deep molecular understanding of the disease.

Questions to Ask Your Doctor About Biomarker Tumor Testing >
from the National Ovarian Cancer Coalition

Downloadable guide with practical questions to support treatment planning. Encourages active participation in care decisions, focusing on biomarker tumor testing. (Also available in Spanish)

Questions to Ask Your Doctor About Genetic Testing for Inherited Mutations >
from the National Ovarian Cancer Coalition

Downloadable guide with practical questions to support treatment planning. Encourages active participation in care decisions, focusing on genetic testing. (Also available in Spanish)

About Genetic Testing >
from Ovarian Cancer Research Alliance

Helpful infographic on biomarker and genetic testing, as well as frequently asked questions.

1C SYMPTOM TRACKING

Symptoms play an important role in how LGSOC is identified, monitored, and managed, yet they are often easy to overlook or explain away.

Many people experience symptoms such as bloating, pelvic or back pain, changes in bowel habits, or fatigue long before receiving an accurate diagnosis. Tracking symptoms over time can support clearer conversations with your care team by reducing the pressure to remember details in the moment and help make patterns more visible to ensure concerns are taken seriously. Symptom tracking can also be useful during treatment, surveillance, or when something feels different and you're not sure why.

The tools below are designed to be simple and flexible and can be tailored to your specific preferences and needs.

RESOURCES TO EXPLORE:

Ovarian Cancer Symptom Diary >
from the National Ovarian Cancer Coalition

Printable tool to help track your symptoms over time and share patterns with your doctor. Supports clear communication during appointments and diagnostic evaluations. (Also available in Spanish)

Symptom Checker >
from STAAR LGSOC Foundation

Interactive tool designed to help you recognize ovarian cancer symptoms. Encourages timely conversations with your doctor.

B.E.A.C.H Symptom Card >
from Ovarcome

Visual symptom awareness card highlighting key ovarian cancer warning signs. Can be used as a quick reference or conversation starter with your doctor.

1D YOUR INTEGRATED CARE TEAM

Navigating LGSOC often involves working with multiple healthcare providers, sometimes across different locations or health systems.

It is important to understand who may be involved in your care, what roles different providers play, and how to advocate for a coordinated approach. Depending on your situation and access to care, your team may include medical or gynecologic oncologists, oncology nurses, pathologists, genetic counselors, and other specialists who support different aspects of your care in addition to your primary care provider.

There are many resources available to find ovarian cancer/LGSOC specialists, prepare for appointments, understand when a second opinion can be helpful, and stay organized as your care evolves.

RESOURCES TO EXPLORE:

Find a Doctor >
from Ovarian Cancer Research Alliance

Searchable database to locate gynecologic oncologists and ovarian cancer specialists. Designed to help you find experienced providers close to home or nationally.

Best Ovarian Cancer Doctors: Where to Turn >
from Not These Ovaries

Guidance on finding experienced gynecologic oncologists and specialty care. Emphasizes the importance of expertise, second opinions, and treatment at medical centers that have extensive experience treating individuals with ovarian cancer.

Who's Who on Your Treatment Team >
from Sharsheret

Explains the roles of different healthcare providers involved in cancer care. Helps you understand who does what and how team members work together.

Questions to Consider When Choosing Your Treatment Team >
from Sharsheret

Practical checklist of questions to ask when selecting providers. Supports informed decision-making and patient self-advocacy.

Share Your Healthcare Team >
from Sharsheret

Tool to help you organize and share information about your care team. Useful for coordination across providers and support networks.

Seek a Specialist >
from the Foundation for Women's Cancer

Searchable database to find gynecologic oncologists who can manage your care from diagnosis to completion of treatment.

RESOURCES TO EXPLORE *(CONTINUED)*:

Questions to Ask Your Doctor: The Gynecologic Oncologist's Role in Your Care >

from the National Ovarian Cancer Coalition

These questions should help you have a clear conversation with your gynecologic oncologist about your care. (Also available in Spanish)

Questions to Ask Your Doctor: The Social Worker's Role in Your Care >

from the National Ovarian Cancer Coalition

These questions should help you have a clear conversation with your social worker about your care. (Also available in Spanish)

Questions to Ask Your Doctor: The Patient Navigator's Role in Your Care >

from the National Ovarian Cancer Coalition

These questions should help you have a clear conversation with your patient navigator about your care. (Also available in Spanish)

2 TREATMENT & CARE DECISIONS

2A TREATMENT OPTIONS NAVIGATION

2B CLINICAL TRIALS OVERVIEW

2A TREATMENT OPTIONS NAVIGATION

Treatment decisions in LGSOC can feel complex, particularly because treatment approaches may differ from those used for other types of ovarian cancer and are highly individualized. LGSOC responds differently to certain therapies, and there are different options available for treatment after an initial diagnosis and if the cancer returns (recurs). Understanding these differences can help you feel more prepared for conversations with your care team.

Learn more about the different treatment paths, why recommendations change over time, and support thoughtful conversations with your care team.

After initial diagnosis

- For most individuals, treatment begins with surgery to remove as much of the cancer as possible. Surgery plays a central role in LGSOC care and is often the most important first step.
- After surgery, next steps may vary. Unlike high-grade serous ovarian cancer, chemotherapy does not tend to be as effective in LGSOC, because the cancer cells grow more slowly. Some people may still receive chemotherapy, while others may be treated with hormone-based therapies or enter a period of close monitoring, depending on factors such as disease stage, surgical outcome, and individual preferences.
- Because there is no single standard approach that fits everyone, it is common for people with LGSOC to receive different recommendations and to have questions about why their treatment plan may differ from someone else's. These conversations can be confusing, and seeking care from providers familiar with LGSOC is especially helpful at this stage.

If the cancer recurs

- The possibility of cancer returning is a difficult reality, with about 4 out of 5 individuals experiencing a recurrence. If this happens, treatment plans often need to change and adapt as the disease progresses. Remember, you are not alone, and your care team is there to support you through each step.
- Because treatment at recurrence may look different from initial treatment, people often revisit earlier assumptions about what is "typical" or expected. Treatment options may include additional surgery, hormone therapy, participation in clinical trials, or targeted treatments that focus on specific features of the tumor.
- Importantly, new targeted therapies have now been FDA approved specifically for recurrent LGSOC, marking a significant change in the treatment landscape.

RESOURCES TO EXPLORE:

Guide to Hormone Therapy in Low-Grade Serous Carcinoma Glossary >
from the Low-Grade Serous Ovarian Cancer Initiative

Defines key terms related to hormone therapy used in LGSOC care. Designed to make treatment conversations and educational materials easier to understand.

Questions to Ask Your Doctor: How Can I Prepare for Treatment? >
from the National Ovarian Cancer Coalition

Downloadable guide with practical questions to support treatment planning. Encourages active participation in care decisions.

Developments & Advances in Low Grade Serous Ovarian Cancer (Webinar) >
from Ovarcome

Video webinar explaining treatment options for women with LGSOC. The webinar also provides details on clinical trials and treatments in the pipeline.

Understanding Low-Grade Serous Ovarian Cancer: Treatments, Trials, and What's Next >
from SHARE Cancer Support feat. Dr. David Gershenson

Expert-led discussion on current treatment options and latest research in LGSOC.

Understanding Treatment Options for LGSOC (Presentation) >
from STAAR LGSOC Foundation

Recorded presentation from the STAAR LGSOC Patient Conference, providing information on how LGSOC has been treated, how existing treatments can be repurposed to treat LGSOC, and an overview of the FDA approval process for treatments.

Teal Talk Episode FDA Approval for Recurrent Low-Grade Serous Ovarian Cancer: A New Era in Treatment >
from National Ovarian Cancer Coalition

Part of the Teal Talk Podcast series, this episode focuses on the approval of avutometinib and defactinib for treatment of recurrent LGSOC with KRAS mutation. Topics include side effects, symptom management, and future outlook.

A Guide to LGSOC Treatment >
from Not These Ovaries

Informational page that details LGSOC treatment and a new FDA-approved treatment for KRAS-mutated recurrent LGSOC. The page provides additional information on genetic testing and next steps in seeking treatment.

2B CLINICAL TRIALS OVERVIEW

Clinical trials play an important role in advancing research and expanding treatment options for people living with LGSOC. Because LGSOC is rare, participation in research has been a key driver of what is currently understood about the disease and how it is treated.

Clinical trials may be available at different points in care, including early after diagnosis, during recurrence, or when considering a change in treatment. For many people, the idea of a clinical trial can bring up questions, uncertainty, or concern. You may wonder what participation involves, how trials are designed, or whether a study is appropriate for your specific diagnosis and treatment history. Others may not realize that clinical trials can be considered alongside standard care, rather than only as a last option.

Many resources exist to help you understand how clinical trials work, what participation may involve, and how to explore trials that are specific to LGSOC. The resources are designed to support informed conversations with your care team, who will be able to provide more tailored recommendations.

RESOURCES TO EXPLORE:

About Clinical Trials >
from Ovarian Cancer Research Alliance

Overview of clinical trials and explanation of different trial phases. Supports informed decision making when considering clinical trial options. Offers a free clinical trial navigator match tool and 1:1 trial navigation.

Ovarian Cancer Research >
from the National Ovarian Cancer Coalition

Comprehensive overview of different types of trials and phases and how to find them.

Clinical Trial Navigator >
from Ovarian Cancer Research Alliance

Interactive questionnaire that helps match patients to relevant clinical trials. Designed to simplify finding clinical trials that match your diagnosis and treatment history. Provides access to Clinical Trial Navigators who can help you find trials and connect you to sites.

Clinical Trials for Low-Grade Serous Ovarian Cancer >
from Low-Grade Serous Ovarian Cancer Initiative

Curated list of clinical trials focused specifically on LGSOC. Can help you stay informed about emerging treatment options.

RESOURCES TO EXPLORE *(CONTINUED)*:

Questions to Ask Your Doctor About Clinical Trials >
from the National Ovarian Cancer Coalition

Downloadable guide with practical questions to support treatment planning. Encourages active participation in care decisions, focusing on clinical trials. (Also available in Spanish)

Understanding Clinical Trials in Ovarian Cancer >
from the National Ovarian Cancer Coalition

Animated educational resource explaining what clinical trials are, how they are conducted, and why they are important for patients with ovarian cancer. (Also available in Spanish)

Teal Talk Episode: Clinical Trials for Ovarian Cancer: Hope, Options, and Survivor Perspective >
from the National Ovarian Cancer Coalition

This episode focuses on how clinical trials work and why they offer real hope in advancing ovarian cancer treatment. Hear insights from a 10-year survivor on trust, timing, and how patients and physicians are working together to shape the future of care.

ZEAL FOR TEAL: New Advances in Low Grade Serous Ovarian Cancer >
from Ovarcome feat. Dr. Rachel Grisham

Video recording from 2026 annual survivorship event featuring LGSOC expert speaking about emerging targets and recent clinical trials.

Let's Discover the Power of Clinical Trials as We Ovarcome Together! >
from Ovarcome

Educational video and FAQs that explain clinical trials, study protocols, potential benefits and risks of participating in a trial, and a comprehensive list of 20 questions to ask the research team. Helps you make an informed decision about whether participation might be right for you.

Clinical Trials: A Start >
from Sandy Rollman Ovarian Cancer Foundation

A downloadable brochure that provides an overview of the basics about clinical trials, including design, oversight, informed consent, privacy, and publication of results.

STAAR Patient Conference: Clinical Trials for Low-Grade Serous Ovarian Cancer >
from STAAR LGSOC Foundation feat. Dr. Rachel Grisham

Recorded discussion from an expert on the clinical trial structure, including how to find an appropriate clinical trial and what trials are currently available for LGSOC.

3 SEXUAL HEALTH, FERTILITY PRESERVATION & MENOPAUSE

3A FAMILY PLANNING AND FERTILITY PRESERVATION

3B MENOPAUSE AND HORMONAL CHANGES

3C SEXUAL HEALTH AND INTIMACY

3A FAMILY PLANNING AND FERTILITY PRESERVATION

Fertility and family planning questions often surface differently in LGSOC because care may involve ovarian surgery and longterm treatment decisions that affect reproductive health over time. These considerations can arise early, recur later, or feel unexpectedly urgent depending on how care unfolds.

You may find yourself needing to make major decisions about fertility, reproductive health, and future family building under time pressure. It is important to ensure you have all the facts about fertility-related considerations before, during, and after treatment, including fertility-sparing options and preservation strategies. The resources support both practical planning and personal reflection, whether you are actively making fertility-related decisions now or processing changes to your fertility and family building over time.

RESOURCES TO EXPLORE:

Fertility-Sparing Treatment for Gynecologic Cancer >
from SHARE Cancer Support

Recorded educational session explaining fertility-sparing options and considerations. Useful if you are weighing treatment decisions with future family planning in mind.

Fertility Sparing Surgery in Ovarian Cancer: Preserving Hope for Future Families >
from Not These Ovaries

Explains when fertility-sparing surgery may be an option and what you should consider. Focuses on how to have informed discussions with your care team.

TEAL TALK: Preserving Possibility: Fertility, Hope, and Family After Cancer >
from National Ovarian Cancer Coalition

Learn how treatments like chemotherapy and radiation can impact fertility—and discover the latest options available to preserve it. This episode offers expert insight and hope for women facing fertility challenges after cancer.

Oncofertility: Fertility Preservation for Patients With Gynecologic Cancer (2025) >
from Ovarian Cancer Research Alliance

Webinar featuring Dr. Joseph Letourneau discusses oncofertility and how to make informed decisions about your reproductive future before, during, and after cancer treatment.

3B MENOPAUSE AND HORMONAL CHANGES

Hormonal changes are a common part of living with LGSOC, and, for many people, these changes can happen suddenly rather than gradually. Surgery to remove the ovaries may lead to surgical menopause, causing an abrupt drop in hormones and the onset of symptoms all at once, regardless of age or where you may have been in menopause before treatment. This can feel jarring, unexpected, and difficult to prepare for.

Symptoms of menopause may include hot flashes, sleep disruption, mood changes, vaginal dryness, changes in sexual health, bone health concerns, and shifts in energy or concentration. When these changes occur abruptly, they can feel more intense and may affect daily life, relationships, and emotional wellbeing in ways that are hard to anticipate.

Learn more about why menopause and hormonal changes occur in LGSOC, what symptoms are common, and how these changes may show up over time.

RESOURCES TO EXPLORE:

Menopause After Ovarian Cancer: What You Need to Know, Ways to Manage Symptoms, and **Hormones, Health, and Healing** >
from the National Ovarian Cancer Coalition

Articles explaining the physical symptoms and emotional changes that occur during menopause after ovarian cancer. Designed to help you make informed decisions about your care and symptom management.

Track Your Menopause Journey >
from the National Ovarian Cancer Coalition

A tracking tool to monitor menopause-related symptoms over time. Helps you communicate the severity and patterns of your symptoms with your doctor.

Menopause, Sexual Health and Fertility Resources >
from Ovarian Cancer Research Alliance

This hub connects you to trusted external resources about menopause. Useful for exploring multiple dimensions of hormonal health.

When Cancer Treatment Causes Menopause – The Physical Impact and The Emotional Impact >
from SHARE Cancer Support

Two educational videos addressing physical and emotional symptoms of menopause. Offers validation and practical coping strategies.

Coping with Early Menopause After Gynecologic Cancer >
from SHARE Cancer Support

Dr. Melissa Frey and Dr. Deanna Gerber discuss causes of early menopause, what symptoms to look for, and the best ways to manage them.

3C SEXUAL HEALTH AND INTIMACY

Sexual health and intimacy are an important part of quality of life, yet they are often underdiscussed in LGSOC care.

Changes related to LGSOC, surgery, or treatment can affect comfort, desire, body image, and emotional connection. These changes may include pain during intimacy, vaginal dryness, pelvic discomfort, fatigue, or feeling disconnected from your body. Some individuals describe feeling pressure to "push through" discomfort or uncertainty, particularly when these topics are not often a priority discussion point in healthcare settings.

Please know that sexual health concerns are real, common, and valid, and that pain or discomfort should not be accepted as something you simply have to live with. The resources address both physical and emotional aspects of sexual health, including pain management, pelvic floor support, communication, and rebuilding intimacy over time.

RESOURCES TO EXPLORE:

Uniquely You: Embracing Sex and Intimacy After Cancer >
from the Foundation for Women's Cancer

Educational course addressing sexual health changes after cancer. Focuses on communication, body image, and intimacy.

Sexuality & Intimacy: Your Guide >
from the Foundation for Women's Cancer

Downloadable fact sheet covering common sexual health concerns. Designed to support conversations with partners and healthcare providers.

Sexual Health and Ovarian Cancer >
from STAAR LGSOC Foundation

Informative video sharing practical solutions for reducing pain during sex. Emphasis on communication and caring between partners.

Dating, Sexual Health, and Intimacy >
from Ovarian Cancer Research Alliance

Online resources addressing relationships, dating, and intimacy after cancer. Emphasizes practical guidance and emotional validation.

Sexual Health and Intimacy: Next Steps for Recovery >
from Ovarian Cancer Research Alliance

A frank conversation around sexual health and finding ways to regain intimacy after cancer. Dr. Sharon Bober addresses your concerns and answers your questions about strategies to improve your physical, emotional, and sexual well-being.

RESOURCES TO EXPLORE *(CONTINUED)*:

Reclaiming Your Sexuality After Gynecologic Cancer >
from SHARE Cancer Support

Nicole Dreibelbis and Nora Lersch, nurse practitioners in gynecological oncology who run clinics for cancer patients and survivors who are dealing with sexual health issues, provide strategies for navigating sexual health after gynecologic cancer and reclaiming this side of yourself.

Sexual Health and Ovarian Cancer Presentation >
from STAAR LGSOC Foundation

Presentation from the STAAR LGSOC Patient Conference discussing the kinds of sexual problems women with LGSOC can experience and practical solutions for dealing with sexual dysfunction.

Teal Talk: Body Image and Intimacy After Ovarian Cancer >
from the National Ovarian Cancer Coalition

This episode focuses on how ovarian cancer treatment can affect body image, sexual health, and relationships. Learn practical strategies for navigating these changes and rebuilding confidence and connection after treatment.

Let's Talk About It: Ovarian Cancer (Connecting with Your Body: Sex & Intimacy) >
from SHARE Cancer Support

Video discussion focused on rebuilding connection and confidence. Addresses physical and emotional aspects of intimacy.

Communicating with Your Partner About Sexual Changes During Treatment >
from Unite for HER

Recording from workshop exploring sexual health, pleasure, and connection in the context of cancer and healing featuring Dr. Sabitha Pillai-Friedman.

Let's Talk About It: Ovarian Cancer – Sex and Intimacy After Cancer >
from SHARE Cancer Support

Explores changes in sexual health following treatment. Provides coping strategies and reassurance.

Healing Through Pelvic Floor Physical Therapy >
from SHARE Cancer Support

Educational video explaining pelvic floor therapy and its benefits. Useful for managing discomfort and improving quality of life.

4 LIVING WITH LGSOC

4A EVERYDAY WELLNESS

4B NUTRITION AND LGSOC

4C LONG-TERM CARE, SURVIVORSHIP, AND RECURRENCE MONITORING

4A EVERYDAY WELLNESS

Living with LGSOC often involves balancing symptoms, treatment side effects, and the demands of everyday life that can affect your overall functioning and ability to work and participate in daily routines. Integrative wellness approaches can be implemented to improve quality of life, including managing fatigue and pain, and movement (such as gentle activity, stretching, or physical therapy).

In addition to managing physical symptoms, you may also be navigating work responsibilities, caring for family members, and maintaining routines that are important to your sense of normalcy and independence. The resources in this section include practical tools and supportive programs that can help you adapt your daily activities, conserve energy, and find ways to stay engaged in everyday roles as your needs, capacity, or priorities shift over time.

RESOURCES TO EXPLORE:

Living with Ovarian Cancer >
from the National Ovarian Cancer Coalition

Quality of life booklet covering symptom management, side effects, and daily living strategies. Designed for ongoing reference throughout survivorship.

Survive and Thrive >
from the Sandy Rollman Ovarian Cancer Foundation

Survivorship program focused on quality of life, wellness, and community connection. Addresses the physical, emotional, and practical challenges of living with ovarian cancer.

Unite for HER Video Library >
from Unite for HER

Collection of educational and wellness videos addressing integrative therapies and supportive care. Focuses on holistic approaches to living with cancer.

Ovarian Cancer Pain: 10 Ways to Manage It and Take Back Your Quality of Life >
from Not These Ovaries

Provides concrete, evidence-based ways to manage ovarian cancer pain, from medications and procedures to integrative therapies and emotional tools. Designed to encourage individuals with ovarian cancer to ask for help and self-advocate.

Movement and Healing: Learn and Experience the Benefits of Movement During GYN Cancer Treatment and Beyond >
from SHARE Cancer Support

Expert-led discussion on the mind-body benefits of exercise and movement.

4B NUTRITION AND LGSOC

Living with LGSOC can bring changes that affect nutrition in different ways, including treatment side effects, fatigue, digestive symptoms, changes in appetite, and the demands of daily life. Additionally, nutritional guidance can help supplement treatment plans to help maintain strength and manage side effects.

Practical, supportive nutrition guidance recognizes that there is no one-size-fits-all plan. The resources are intended to help you explore how nutrition and integrative approaches may support your quality of life, symptom management, and overall wellbeing, while recognizing that needs can change over time and may look different from person to person.

RESOURCES TO EXPLORE:

Diet and Nutrition Webinars >
from Ovarcome

Expert-led webinars addressing nutrition concerns specific to ovarian cancer. Includes practical tips and patient-centered discussion.

Nutrition Resources >
from Unite for HER

Hub for handouts, videos, and recipes for healthy eating and symptom management. Useful as a one-stop shop for nutritional information.

Ina® The Intelligent Nutrition Assistant >
from the National Ovarian Cancer Coalition

Digital nutrition tool offering personalized dietary guidance during and after treatment. Supports symptom management and overall health.

Optimizing Nutrition for Ovarian Cancer Wellness >
from STAAR LGSOC Foundation feat. Erin Pellegrin

Expert-led discussion on the importance of nutrition during and after a cancer diagnosis, as well as strategies to overcome challenges and barriers.

Nutrition Videos >
from the National Ovarian Cancer Coalition

This nutrition video playlist from the National Ovarian Cancer Coalition offers practical, compassionate guidance on eating during and after ovarian cancer treatment. It helps patients navigate side effects, appetite changes, and everyday challenges with simple, realistic nutrition strategies to support strength and recovery.

RESOURCES TO EXPLORE *(CONTINUED)*:

Seasoned with Strength – A Free Ovarian Cancer Cookbook >

from the National Ovarian Cancer Coalition

This cookbook offers simple, nourishing recipes and practical nutrition tips designed for those navigating ovarian cancer. Created with real-life challenges in mind, it helps patients and caregivers make meals more manageable while supporting strength, comfort, and connection.

Nutrition During & After Cancer Treatment: Fighting Cancer with your Fork >

from SHARE Cancer Support

Educational video covering nutrition strategies to support the body during cancer care. Emphasizes practical, evidence-based guidance.

Uniquely You: Eating Well. Living Well. >

from the Foundation for Women's Cancer

Educational course addressing the power of movement as well as eating for wellness, supplements and vitamins, exercise, dietary approaches and complementary alternatives.

4C LONG-TERM CARE, SURVIVORSHIP, AND RECURRENCE MONITORING

Living with LGSOC often does not follow a clear path and, for many people, care continues over years and may include ongoing treatment, regular monitoring, or periods of watchful waiting. This long-term nature can be physically and emotionally demanding, especially when life moves forward but uncertainty remains.

Survivorship with LGSOC often involves regular follow-up visits, scans, and lab work, sometimes every few months. While monitoring can provide reassurance, it can also bring stress, anxiety, and fear of recurrence, particularly as appointments approach or when results are unclear.

Similar to treatment discussions, there is an individualized approach to LGSOC long-term, including recurrence monitoring, follow-up planning, and staying organized over time. Further, survivorship is not only about medical care, but about learning how to live alongside uncertainty, manage ongoing symptoms or side effects, and adjust as needs change.

RESOURCES TO EXPLORE:

Resource Guide for Those with Recurrent Ovarian Cancer >
from the National Ovarian Cancer Coalition

Detailed guide focused on recurrence education and coping strategies. Supports informed surveillance and care planning. (Also available in Spanish)

Understanding Recurrence >
from Ovarian Cancer Research Alliance

Explains what recurrence means, common signs, and next steps. Designed to reduce uncertainty and support preparedness.

Ovarian Cancer Survivorship Plan >
from Foundation for Women's Cancer

Structured survivorship care plan template. Helps you track your symptoms, follow-up care, and long-term health needs.

Survivorship Program >
from Sharsheret

Programs and resources, including lifestyle guides, non-medical financial support, and clinical team/ peer mentor support, for life beyond ovarian cancer.

Survivorship Workshop >
from Ovarian Cancer Research Alliance

A 3-part series addressing topics including redefining your identity after diagnosis, managing late effects from treatment, managing fear and how to look forward, and overall wellness.

5 EMOTIONAL, SOCIAL, & PRACTICAL SUPPORT

5A EMOTIONAL HEALTH AND MENTAL WELLBEING

5B CONNECTING WITH A SUPPORTIVE NETWORK

5C INSURANCE, FINANCIALS, AND PRACTICAL SUPPORT

5A EMOTIONAL HEALTH AND MENTAL WELLBEING

Living with LGSOC can take an emotional toll that changes over time, and many people describe feeling a mix of fear, anxiety, grief, frustration, or emotional exhaustion. These feelings are common and understandable, especially when living with a disease that often involves uncertainty and ongoing monitoring.

Emotional challenges in LGSOC may show up in different ways, including anxiety before scans or test results ("scanxiety"), worry about recurrence, difficulty making long-term plans, or feeling disconnected from others who may not fully understand what you are experiencing. Some people also describe the strain of looking "fine" on the outside while managing significant emotional or physical burdens internally.

Emotional support may come from different places, including finding community, connecting with trained counselors, or using tools that help you cope during particularly stressful moments.

RESOURCES TO EXPLORE:

Steps: Support for Living with Gynecologic Cancer >
from Ovarian Cancer Research Alliance

Provides 10 free sessions with an oncology counselor designed to help you cope with an ovarian cancer diagnosis, treatment, and beyond.

Patient Support Line >
from Ovarian Cancer Research Alliance

Direct support line connecting patients to trained oncology specialists. Offers personalized resource navigation and emotional support.

Mental Health Support for Ovarian Cancer Survivors and Caregivers >
from the National Ovarian Cancer Coalition

Overview of mental health services available to you and your caregivers. Encourages proactive emotional care.

OvarCare Program >
from Ovarcome

Personalized support program connecting you to tailored resources. Addresses emotional, practical, and financial needs.

RESOURCES TO EXPLORE *(CONTINUED)*:

Let's Talk About It: Ovarian Cancer – Scanxiety >
from SHARE Cancer Support

Educational video addressing anxiety related to scans and surveillance. Offers coping strategies to address common fears.

Empowered Living & Wellness Passport Programs >
from United for HER

Free wellness programs for those who have experienced ovarian and breast cancer and are interested in learning more about support resources.

Ovarian Cancer Support Line >
from SHARE Cancer Support

Confidential support line for you and your caregivers. Provides emotional support and navigation assistance.

5B CONNECTING WITH A SUPPORTIVE NETWORK

Connecting with others who understand the realities of LGSOC can provide comfort, perspective, and practical insight.

Learn more about available peer support opportunities, advocacy communities, and different ways to engage, allowing you to choose the level and type of connection that feels right for you.

RESOURCES TO EXPLORE:

Local Ovarian Cancer Organization Finder >
from the World Ovarian Cancer Coalition

Directory to locate local advocacy and support organizations worldwide. Helps connect you with community-based resources.

Advice from the LGSOC Community >
from the Low-Grade Serous Ovarian Cancer Initiative

Shared insights and reflections from other individuals living with LGSOC. Offers peer perspective and encouragement.

Connect with a Peer Supporter >
from Sharsheret

Program connecting you to trained peer supporters. Emphasizes culturally responsive and personalized support.

Woman to Woman Peer Mentor Program >
from Ovarian Cancer Research Alliance

One-to-one peer support program that matches you with trained survivor mentors. Focuses on shared experience and emotional support.

Survivor Peer Support Groups >
from the National Ovarian Cancer Coalition

Peer-led survivor support groups for connection and shared understanding. Available in multiple formats.

With a Little Help From Her Friends >
from Sandy Rollman Ovarian Cancer Foundation

Peer-to-peer mentoring program for newly diagnosed women, connecting ovarian cancer patients with individuals who have shared a similar experience.

LGSOC Initiative Facebook Groups >
Led by patient and caregiver communities

The LGSOC Facebook Peer Support Group offers a supportive and understanding community for individuals diagnosed with LGSOC and their caregivers. Hosted by the LGSOC Initiative and moderated by fellow patients and caregivers, respectively, the groups provide a safe space for you to connect, ask questions, and receive encouragement.

Low-Grade Serous Ovarian Cancer Support Group >
from SHARE Cancer Support

The group offers a safe and supportive environment for individuals to share their experiences, ask questions, and connect with others who are also navigating LGSOC.

5C INSURANCE, FINANCIALS, AND PRACTICAL SUPPORT

Managing LGSOC often comes with practical challenges that extend beyond medical care. Costs related to care, travel, childcare, meals, or household needs can accumulate, and insurance coverage may feel confusing or hard to navigate especially when plans change or care is received across different settings. Many people find themselves navigating complex systems while also coping with the physical and emotional demands of the disease.

Across the LGSOC community, practical support options exist that may help reduce some of that burden, including insurance navigation, financial assistance programs, workplace and disability considerations, and help with everyday needs.

RESOURCES TO EXPLORE:

OvarCare Program >
from Ovarcome

Relevant for financial navigation, this program connects individuals to tailored assistance. Addresses insurance, logistics, and daily needs.

Your Unique Story: Addressing Financial Challenges >
from the Foundation for Women's Cancer

Educational content addressing the financial impact of cancer. Encourages proactive planning and communication.

Financial Assistance Resources >
from Ovarian Cancer Research Alliance

Curated list of financial aid programs and support services. Serves as a centralized starting point.

Qualify for Social Security Benefits for Gynecologic Cancer >
from the Foundation for Women's Cancer

Offers guidance on managing the financial aspects of gynecologic cancer care, including insurance, disability benefits, and assistance programs. Helps you and your caregivers better understand costs and access available support.

National Ovarian Cancer Coalition Financial Assistance Program >
from the National Ovarian Cancer Coalition

Provides limited financial assistance for eligible individuals. Designed to help offset treatment-related costs.

Common Financial Terms Explained >
from the Foundation for Women's Cancer

Plain language guide defines common financial and insurance terms encountered during cancer care. Helps patients and caregivers better understand billing, coverage, and cost-related conversations.

Patient Navigation >
by SHARE Cancer Support

Individualized assistance to patients, families, and caregivers to help overcome healthcare system barriers and facilitate timely access to quality health and psychosocial care through all phases of the cancer experience.

6 SUPPORTING CAREGIVERS

SUPPORTING CAREGIVERS

Caregivers play an essential role in supporting individuals living with LGSOC.

They may be partners, spouses, parents, siblings, adult children, and friends and often step into their role suddenly, without preparation or guidance. Caregiving can involve managing appointments, providing emotional support, helping with daily tasks, and carrying worry that is rarely spoken aloud.

Because LGSOC is often a long-term condition, caregiving may continue for years and change as the disease evolves. Caregivers may experience their own emotional strain, fatigue, anxiety about recurrence, or difficulty balancing caregiving with work, family responsibilities, and their own health. Caregiving does not have to be done alone, and resources exist within the broader LGSOC community to support the caregiver experience.

RESOURCES TO EXPLORE:

Caregiver Peer Support Group >
from the National Ovarian Cancer Coalition

Caregiver-focused peer support program. Provides connection and shared coping strategies.

Caring for the Caregiver: Maintaining Your Health as a Caregiver >
from the National Ovarian Cancer Coalition

Guide to addressing caregiver health, stress, and sustainability. Encourages caregivers to prioritize their own wellbeing.

Caregiving in Ovarcoming >
from Ovarcome

Comprehensive caregiver booklet offering practical and emotional guidance. Addresses daily challenges and long-term support.

Compassionate Caregivers: Navigating Cancer's Challenges >
from the Foundation for Women's Cancer

Series of six modules that helps caregivers support loved ones by becoming active participants in the care team and gaining skills to prioritize their own mental health.

Caring for the Caregiver: Exploring Medical PTSD and Caregiver Burnout >
from SHARE Cancer Support

Slide presentation addressing the often-overlooked psychological impact of caregiving. Covers the unique challenges caregivers face in balancing their own wellbeing with the demands of supporting a loved one through cancer treatment and how to practice self-care.

RESOURCES TO EXPLORE *(CONTINUED)*:

Staying Connected Loved Ones >
from Ovarian Cancer Research Alliance

Offers a weekly meeting for loved ones to talk, share, and offer encouragement to each other as they navigate their new role as caregiver.

Caregiver Support Group >
from SHARE Cancer Support

Provides a space for caregivers to meet and share strategies for caring for a loved one without losing yourself.

CLOSING & APPENDIX

LOOKING AHEAD & ADVOCATING FOR CONTINUED PROGRESS

CLOSING

Some individuals with LGSOC find meaning in sharing their experiences to support education, awareness, and progress in ovarian cancer care. Across the LGSOC community, there are opportunities for advocacy, ranging from education and storytelling to community engagement.

As you navigate your personal journey, you may find meaning in involvement at a level that feels right for you.

RESOURCES TO EXPLORE:

Advocating for Better Outcomes: Ovarian Cancer and You >
from SHARE Cancer Support

Educational video explaining the role of patient advocacy. Encourages engagement at personal and community levels.

Local Advocacy: Getting Started in Your Community >
from Ovarian Cancer Research Alliance

Introductory resources for individuals interested in advocacy. Provides tools and guidance for community involvement.

Awareness and Fundraising Resources >
from the Low-Grade Serous Ovarian Cancer Initiative

Downloadable posters, social media assets, and other resources to help raise awareness of LGSOC in your community or plan a fundraiser.

Ovarcoming: Stories of Hope & Healing >
from Ovarcome

Memoir about finding deeper appreciation for life's precious moments, exploring the power of community and the strength that lies within us all. Ovarcoming Cancer: Celebrating Life. Ovarcome to ship to any patient for free, request via info@ovarcome.org.

ABOUT THE ORGANIZATIONS

For more information about each organization and to review the latest resources and events offered by each, click the link below to navigate to their website.

STAAR – Low-Grade Serous Ovarian Cancer Foundation – STAAR, which stands for **S**urvive. **T**hrive. **A**dvocate. **A**dvance. **R**esearch., is dedicated to supporting ovarian cancer survivors through education, advocacy, and research-focused initiatives. They offer symptom awareness tools, educational content, and resources to support informed care decisions. The organization emphasizes patient empowerment and long-term survivorship.

Not These Ovaries – Not These Ovaries is a patient-driven nonprofit dedicated to improving outcomes for those affected by LGSOC and borderline ovarian tumors (BOT). The organization empowers patients and caregivers by providing disease-specific education, resources on biomarkers and treatment options, and guidance on finding experienced healthcare providers. It also invests in research targeting these understudied areas. 100% of donations go directly to supporting patients and funding research.

Ovarcome – Ovarcome is an international ovarian cancer foundation providing education, support, and advocacy for patients and families. They offer webinars, peer support programs, and practical resources addressing both the physical and emotional aspects of ovarian cancer. The organization supports individuals at all stages of the disease, including those experiencing recurrence.

Sandy Rollman Ovarian Cancer Foundation – The Sandy Rollman Ovarian Cancer Foundation focuses on improving early detection, treatment, and quality of life for individuals affected by ovarian cancer. Through education, advocacy, and survivorship programs, they support both patients and caregivers. The foundation also works to educate future healthcare providers through survivor-led initiatives.

Low-Grade Serous Ovarian Cancer Initiative – The Low-Grade Serous Ovarian Cancer Initiative is focused exclusively on supporting individuals with LGSOC. They provide education, community resources, and information about research and clinical trials specific to this rare subtype of ovarian cancer. The organization also amplifies patient voices and works to increase awareness of LGSOC and support research.

National Ovarian Cancer Coalition (NOCC) – The National Ovarian Cancer Coalition is dedicated to supporting individuals impacted by ovarian cancer through education, advocacy, and patient-centered programs. They offer a wide range of educational resources, peer support programs, and practical tools for patients and caregivers. Their services are designed to provide support from diagnosis through survivorship.

ABOUT THE ORGANIZATIONS *(CONTINUED)*

Ovarian Cancer Research Alliance (OCRA) – Ovarian Cancer Research Alliance is the largest global organization dedicated to advancing ovarian cancer research while also providing patient support and education. They offer clinical trial navigation, genetic testing programs, peer mentoring, resource navigation, and a wide range of education and support programs. OCRA's Community Accelerated Research Exchange, which includes the Living Lab ovarian and uterine cancer patient registry, is propelling science and finding the necessary answers around prevention, diagnosis, treatment, and symptom management.

World Ovarian Cancer Coalition (WOCC) – The World Ovarian Cancer Coalition is a global alliance of advocacy organizations working to improve outcomes for individuals with ovarian cancer worldwide. They focus on awareness, early diagnosis, and equitable access to care across countries. WOCC also amplifies patient perspectives through global data, storytelling, and collaboration.

Foundation for Women's Cancer – The Foundation for Women's Cancer is dedicated to advancing research, education, and awareness of gynecologic cancers, including ovarian cancer. They provide trusted educational resources, survivorship tools, and patient education programs developed in collaboration with clinical experts. The organization focuses on empowering individuals with knowledge to support informed decision-making throughout their care.

SHARE Cancer Support – SHARE Cancer Support provides free emotional support, education, and advocacy to individuals affected by breast and gynecologic cancers. Its programs include peer-led support from trained survivors through support lines and support groups, as well as educational webinars led by healthcare professionals and subject-matter experts. SHARE fosters connection, shared experience, and compassionate support throughout diagnosis, treatment, and survivorship.

Sharsheret – Sharsheret provides personalized support, lifesaving education, financial assistance and genetic counseling to empower those faced with or at increased genetic risk of breast cancer and ovarian cancer. While Sharsheret's expertise is in young women and Jewish families as related to breast cancer and ovarian cancer, Sharsheret programs serve all women and men.

Unite for HER – Unite for HER provides integrative care and wellness resources to support individuals during and after cancer treatment. Their programs focus on nutrition, movement, stress management, adherence to treatments, management of side effects, and emotional wellbeing. They aim to improve quality of life through holistic, patient-centered support.