

Talking about Squamous Cell Skin Cancer

A GUIDE FOR TALKING ABOUT TREATMENT WITH YOUR CANCER CARE TEAM

This guide can help you take control and have better discussions with your health care team after a diagnosis of Squamous Cell Skin Cancer. This type of cancer is also known as Cutaneous Squamous Cell Carcinoma (cSCC) or Squamous Cell Carcinoma of the Skin. Inside this guide, you'll find a quick overview of this type of cancer, treatment options, questions to ask your health care team, a worksheet to help you set your own goals, and resources for information and support.

If you have a different kind of skin cancer (Basal Cell, Melanoma, or Merkel Cell), visit www.CancerSupportCommunity.org/skin-cancer for information that is right for you.

WHAT IS SQUAMOUS CELL SKIN CANCER?

cSCC is the second most common type of skin cancer. It starts in the top layer of the skin called the epidermis. Most cSCC growths show up on sun-exposed areas of the body, especially the face and neck. But they can occur in other areas too. Around 95% of cSCC is “local” and found early when it can be cured. But sometimes it can grow back, and in rare cases it spreads to other parts of the body.

OVERVIEW OF TREATMENT FOR SQUAMOUS CELL SKIN CANCER

Treatment for cSCC will depend in your cancer stage, risk for recurrence, and health. Below is an explanation of the stages of cSCC and the treatment options your health care team may recommend.

Stage	Description	Treatment Options
Local, Low Risk cSCC	Cancer is small tumors with a low chance of the cancer spreading or recurring after treatment.	Surgery <ul style="list-style-type: none"> • Excision – the entire growth is removed along with a surrounding border of normal skin • Curettage and electrodesiccation – the tumor is scraped down to its base followed by pulses of electrical energy Radiation therapy – uses high-powered energy beams to kill cancer cells and shrink tumors
Local, High Risk cSCC	Cancer is in one location but has a higher chance of spreading or recurring after treatment.	Surgery <ul style="list-style-type: none"> • Lymph node dissection – removes lymph nodes and checks them for cancer • Mohs surgery – removes skin cancer one layer at a time until normal, healthy tissue is reached Chemotherapy – uses drugs to kill fast-growing cells like cancer Radiation therapy – uses high-powered energy beams to kill cancer cells and shrink tumors
Advanced or Metastatic cSCC	Cancer has spread aggressively in one area or spread to other parts of your body	Immunotherapy – strengthens the body’s immune system so it can fight cancer better Targeted therapy drugs - keep cancer from growing and spreading with less harm to cells that are not cancer Clinical trial – research studies that test new treatments

QUESTIONS TO ASK ABOUT YOUR DIAGNOSIS

- What kind of skin cancer do I have? _____
- Where is my cancer located? _____
- Has the cancer spread? Is the cancer considered “advanced”? _____
- Does the cancer have a high chance of returning? _____

Your health care team may give you a choice of treatment plans. You may be able to help decide what best fits your goals and preferences.

If you have advanced cSCC, and choose not to receive treatment, think about your goals for the care that you receive. Possible goals may be to live as long and as well as possible, contribute to progress by taking part in research, make it to a special event/milestone, or find cutting edge treatments.

Whether you have advanced or local cSCC, make sure you ask questions and discuss any concerns with your health care team. For more information on stages and treatment of squamous cell skin cancer, visit

www.CancerSupportCommunity.org/squamous-cell-carcinoma

TIPS FOR TAKING CONTROL

- Be an active part of your health care team. Write down your questions before each doctor’s visit. Keep a journal to take notes during your visit. Use a binder to include all labs, imaging reports, and other receipts in one place, unless you have a patient portal that does this for you.
- Take pictures of your skin lesions. Monitor for changes and do self-checks.
- Bring someone with you to appointments for support and an extra set of eyes and ears. They can help you take notes. If your loved one cannot be there in person, consider a video call on your phone or computer, or ask your doctor if you can use a recorder or cell phone to record your conversation.
- Ask questions until you understand what is being said. Ask to hear or read information in your first language. You can ask your doctor to draw a picture or compare it to something you already know. Repeat back what you hear for clarity and understanding.
- Know who on your health care team to contact with questions or problems and who to contact after hours.
- Talk to your health care team or financial counselor about ways to manage treatment costs.
- Consider getting a second opinion. You can get a second opinion at any point.

CLINICAL TRIALS

Clinical trials are research studies to test new treatments or learn how to use current treatments better. Today’s standard drugs were once in clinical trials. Tomorrow’s drugs are in them today. In some cases, the treatments with the best chance of success may be available only through clinical trials. Trials are offered for many cancers, at many different stages. Everyone is not eligible for every trial. If you have cancer that has come back or spread, it is especially important to ask about clinical trials.

For more information on clinical trials and how to find them, visit

www.CancerSupportCommunity.org/finding-clinical-trial.

Below are some of the side effects people with Squamous Cell Skin Cancer may have. Think about how often they have affected you since your last visit. Talk to your health care team about how best to manage them.

	Rarely	Sometimes	All the Time
Redness or swelling at the surgery site			
Feeling worried, anxious, overwhelmed, depressed			
Concerns with appearance			
Side Effects for Advanced Squamous Cell Treatment Only			
Nausea, vomiting, diarrhea			
Extreme fatigue, weakness, dizziness, shortness of breath			
Difficulty thinking clearly or remembering (brain fog or chemo brain)			
Changes in taste, poor appetite, or mouth pain/sores			
Pain or nerve problems (neuropathy)			
Skin problems (scarring, rashes, dry skin, or itching)			
Others			

GETTING SUPPORT

Think about people in your life who can help. It might be your spouse or partner, adult children, friends, faith community, support group, or co-workers. You or a caregiver can make a list of the ways each of them can help (childcare, meal prep, housework, transportation, laundry, etc.).

Consider using **MyLifeLine.org** to let friends know what you need and help you stay organized. MyLifeLine also has an online discussion board to talk with others facing advanced basal and squamous cell skin cancer.

Ask your health care team about resources for getting the support you need.

Use trusted websites when searching for information online. (Turn to the back page for trusted organizations.) CSC and these organizations have helplines, online discussion boards, support groups, peer matching services, and more ways to seek support from others who have skin cancer.

THINK ABOUT YOUR TREATMENT & PERSONAL GOALS

When you talk to your doctor about your treatment options, ask about the goals of the treatment and how each treatment might affect the goals that you have for your life. Let each member of your health care team know about your treatment and personal goals.

Physical Health and Well-Being	<i>What is most important for you to be able to do? What are your immediate concerns?</i>
Family and Social Relationships	<i>What is going on in the lives of others that is important to you? Do you have support for your family and yourself?</i>
Work/School	<i>Do you want or need to continue working? Can you adjust your schedule or responsibilities? What paperwork or documentation does your employer need? Do you have any financial concerns?</i>
Community/ Involvement	<i>Are you getting the support you need from your community? Are you able to stay active/ involved in your community?</i>
Other	<i>What else is important to you?</i>

QUESTIONS TO ASK ABOUT YOUR TREATMENT GOALS

- My top goals for treatment are: *[fill in your answers from above]*. _____

- Is the treatment that I am currently on the best treatment for me to meet these goals? _____

- What other treatments are available to me? Are there any new treatments or clinical trials that may be right for me? _____

- What are the side effects of treatment? How will we manage them? _____

- Are there treatments to help with the side effects of the therapies I am receiving? _____

- Would a referral to palliative care help me with the side effects of treatment? _____

QUESTIONS TO ASK YOUR DERMATOLOGIST

- Is the cancer curable by surgery or radiation (local) or not (advanced)? _____

- What are the potential side effects of surgery? _____

- How will my appearance be affected? _____

- What other options for treatment do I have? _____

- Do you work with a multidisciplinary team? Does this clinic have a radiation and medical oncologist that I can consult with? When should I consult with one for treatments other than surgery? _____

QUESTIONS TO ASK YOUR CANCER CARE TEAM

- What are the pros and cons of each treatment option that is available for me? _____

- What are the chances that this treatment may cause short- or long-term side effects? _____

- What are the chances that this treatment may cure me? _____

- Are there treatments or drugs that work as well but would cost me less? _____

- What side effects might I expect, and how can I prepare for them? What side effects should I let you know about? _____

- What can we do to manage these side effects? Is there anything I can do to lessen the side effects? _____

- Could palliative care help manage my side effects? Can you refer me to a palliative care specialist? _____

- The symptoms and side effects that are bothering me the most are: *[from page 2]*. _____

- They are affecting my daily life in these ways:. _____

- What can we do to manage these symptoms?. _____

- How do we know that my treatment is working? _____

- How likely is it that my disease will recur? _____

- What treatment options will I have if my disease recurs? _____

FINANCIAL RESOURCES

Even with health insurance, treatment is expensive. Keeping up with costs can be overwhelming. However, there are many resources that can help.

Talk with your health care team and your pharmacist about the cost of your treatment. Ask your doctor to refer you to an oncology social worker, patient navigator, financial counselor, or nonprofit organization for help managing the financial issues and costs. Ask if there are prescription assistance programs that can help cover all or part of the cost of your medications.

The more you know about your specific treatment plan, the more you can help to reduce unexpected costs. To learn more about ways to manage the cost of treatment, call our Helpline at 888-793-9355 or visit:

www.CancerSupportCommunity.org/cost

Financial Support Resources

Cancer Support Community • 888-793-9355 • www.CancerSupportCommunity.org/Cost

CancerCare • 800-813-4673 • www.cancercare.org/financial

Cancer Financial Assistance Coalition • www.cancerfac.org

Patient Advocate Foundation • 800-532-5274 • www.patientadvocate.org

Advanced Squamous Cell Skin Cancer Resources

Cancer Support Community • 888-793-9355 • www.CancerSupportCommunity.org/squamous-cell-carcinoma

American Cancer Society • 800-227-2345 • <http://bit.ly/ACSbsSkin>

National Cancer Institute • 800-422-6237 • www.cancer.gov/types/skin

National Comprehensive Cancer Network • <http://bit.ly/NCCNsc>

Skin Cancer Foundation • 212-725-5176 • <http://bit.ly/SKINsc>

Cancer Support Community Resources

Cancer Support Helpline® — Have questions, concerns or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon - Fri 9am - 9pm ET.

Open to Options® — Need help making a cancer treatment decision? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

Frankly Speaking about Cancer® — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs. www.CancerSupportCommunity.org/FranklySpeakingAboutCancer.

Services at Local CSCs and Gilda's Clubs — With the help of 170 locations, CSC and Gilda's Club affiliates provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more at a location near you. www.CancerSupportCommunity.org/FindLocation.

Cancer Experience Registry® — Help others by sharing your cancer patient or cancer caregiver experience via survey at www.CancerExperienceRegistry.org.

MyLifeLine — CSC's private, online community allows patients and caregivers to easily connect with friends and family to receive social, emotional, and practical support throughout the cancer journey and beyond. Connect with others affected by cSCC by joining the Advanced Non-Melanoma Skin Cancer online discussion board. Sign up at www.MyLifeLine.org.

Grassroots Network — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at www.CancerSupportCommunity.org/become-advocate.

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The Cancer Support Community provides this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or other health care professionals to answer questions and learn more.

This worksheet is available to download and print yourself at www.CancerSupportCommunity.org/skin-cancer. For print copies of this booklet or other information about coping with cancer, visit Orders.CancerSupportCommunity.org or call 888-793-9355.

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