

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 healthcare 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. This guide will provide a quick overview of cSCC and treatment options, questions to ask your healthcare team, a worksheet to help you set your own goals, and resources for information and support.

If you have a different type of skin cancer (Melanoma, Basal cell, or Merkel cell), visit www.CancerSupportCommunity.org/Skin-Cancer for more information.

WHAT IS SQUAMOUS CELL SKIN CANCER?

cSCC is the second most common type of skin cancer. It starts in the epidermis from the flat squamous cells that lie on top of the basal layer of the skin. The epidermis is the outer layer of skin on the body that you can see and touch. This cancer usually shows up on sun-exposed areas of the body, like the face, ears, and neck. But it can occur in other areas, too. This cancer is usually found early and treated by being removed completely. Sometimes cSCC can grow back, and in rare cases, spread to other parts of the body.



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?

TREATMENT FOR SQUAMOUS CELL SKIN CANCER

Treatment for cSCC depends on your cancer stage, the size and location of the tumor, your treatment preferences, and overall health. Below is a chart that explains the stages of cSCC and the treatment options your healthcare team may recommend.

Stage	Description	Treatment Options
Local, Low Risk cSCC	Cancer is small with a low chance of spreading or recurring after treatment	Surgery <ul style="list-style-type: none">• Excision – the entire tumor is surgically removed along with a surrounding border of healthy tissue• Curettage and Electrodesiccation (C and E) – the tumor is scraped down to its base followed by pulses of electrical energy. This helps prevent bleeding at the site Topical therapies – medicated creams or gels that are applied directly to the affected area Local therapies – such as laser therapy, photodynamic therapy (a cream or gel is applied to make the tumor more sensitive to light treatments), and cryosurgery (liquid nitrogen is applied to the tumor to freeze and destroy it)
Local, High-Risk cSCC	Cancer has not spread, but has a higher chance of spreading or recurring after treatment	Mohs surgery – removes skin cancer one layer at a time until healthy tissue is reached Chemotherapy – uses drugs to destroy or damage fast-growing cells like cancer Radiation therapy – uses high-powered energy beams to kill or damage cancer cells
Advanced or Metastatic cSCC	Cancer has quickly spread in one area or spread to other parts of the body	Immunotherapy – works with the body's immune system to find, attack, and kill cancer cells Targeted therapy drugs - target specific changes in cancer cells that help them grow, divide, and spread. They fight cancer cells with less harm to other cells in the body

For more information on staging and treatment for cSCC, visit www.CancerSupportCommunity.org/Squamous-Cell-Carcinoma.

Below are some of the treatment 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 healthcare team about how to best manage them.

	Rarely	Sometimes	All the time
Redness or swelling at the surgery site			
Irritation or tenderness			
Numbness			
Possible Side Effects For Advanced Squamous Cell Treatment:			
Nausea, vomiting, diarrhea			
Extreme fatigue, weakness, dizziness, shortness of breath			
Difficulty thinking clearly or remembering (brain fog or chemo brain)			
Mouth & throat changes (changes in taste, poor appetite, mouth pain, sores, or burning)			
Pain or nerve problems (neuropathy)			
Skin problems (scarring, rashes, dry skin, itching, peeling, or burning)			
Psychosocial Side Effects You May Experience:			
Feeling worried, anxious, overwhelmed, depressed			
Concerns with appearance			
Other side effects not listed here:			

CLINICAL TRIALS

Clinical trials are research studies to test new treatments or learn how to use current treatments better. They find new and better ways to prevent or treat cancer. A clinical trial may be the only way to gain access to a promising new treatment option. Today, the U.S. Food and Drug Administration (FDA) oversees clinical trials to keep all patients safe.

For more information on clinical trials and how to find them, visit www.CancerSupportCommunity.org/Clinical-Trials.



WORKING WITH YOUR CARE TEAM

Cancer treatment is complicated and changes all the time with new discoveries. You need a healthcare team you can trust to take the best care of you. The team can include doctors, nurses, and other healthcare professionals who work together. This is often called “multidisciplinary care”.

You may also work with a palliative care specialist. **Palliative care** focuses on improving quality of life and helping to reduce pain and other symptoms. Seeing a palliative care specialist can help address many side effects that may arise during treatment. Palliative care is different from hospice care and end-of-life care. It is available to you at any point of your treatment experience.

When choosing your healthcare team, it is important that you can have honest and open conversations. You may be given a choice on what treatment plan is best for you and best fits your goals and preferences. Make sure you share your concerns, ask questions, and feel like you are being heard.

TIPS FOR TAKING CONTROL

Take someone with you to appointments, for support and an extra set of eyes and ears. If you go to an appointment alone, take notes and/or record your conversation with your doctor. Be sure to ask your doctor if it is OK to record.

Be proactive. Talk to your healthcare team or financial navigator about ways to manage treatment costs before you start treatment.

Write down your questions before each doctor's visit. Keep a journal to take notes or use this worksheet to track your progress over time. This can include information about tests, lab work, and the symptoms and side effects you may be experiencing.

Be your own advocate. If you don't feel your healthcare team is addressing your concerns, consider getting a second opinion.

If you do not understand certain words your doctor is using to talk about your cancer, ask them to explain. Your doctor should be able to find other ways to help you better understand your cancer and treatment options.



GETTING SUPPORT

Think about people in your life who can help (your spouse or partner, friends, faith community, support group, or co-workers).

Make a list of things you need help with (childcare, meal prep, laundry, etc.) and who can help with each task. Consider using **MyLifeLine.org** to help you stay organized and let friends know what you need.

Ask your healthcare team about resources for social, emotional, and practical support.

You can also ask for a mentor or to be matched with another person with your specific cancer type.

If you search for information online, make sure that you are using trusted websites.

Turn to the back page of this guide to see a listing of trusted organizations. CSC and many other organizations have helplines, support groups, online discussion boards, and more ways to seek support from others who have cancer.

THINK ABOUT YOUR TREATMENT AND PERSONAL GOALS

When you talk to your doctor about your treatment options, ask about the goals of the treatment and how each treatment might impact your personal goals. Possible personal 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. Let each member of your healthcare team know about your treatment and personal goals. Remember that your goals may change over time.

SETTING YOUR PERSONAL GOALS FOR TREATMENT

Physical Health and Mental Health and Well-being	<i>What is most important for you to be able to do and feel?</i>
Family and Social Relationships	<i>What is going on in the lives of others that are important to you?</i>
Work/School	<i>Do you want or need to continue working? Can you adjust your schedule or responsibilities?</i>
Social Support/Community Involvement	<i>Are you getting the support you need from your loved ones and community? Are you able to stay active/involved in your community?</i>
Other	<i>What else is important to you?</i>



QUESTIONS TO ASK YOUR DERMATOLOGIST

What type of biopsy or surgery am I having?

How soon will I know the results?

What is the plan if the tumor is cancerous (malignant)?

Do you work with a multidisciplinary care team?

If my skin cancer is advanced, does this office have a radiation and medical oncologist that I can consult with? When should I consult with them for treatments other than surgery?

What should I do to prevent skin cancer from coming back?

QUESTIONS TO ASK ABOUT TREATMENT & YOUR GOALS

*Will the treatment you recommend help me meet my goals?
[see your answers from page 7]*

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 clinical trials that may be right for me?

What are the side effects of treatment?

How will we manage the side effects of treatment?

Are there medicines available to help with the side effects?

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

QUESTIONS TO ASK YOUR CANCER CARE TEAM

What are the benefits and risks of each treatment option that is available for me?

Are there other treatments options that work just as well but would cost me less?

The symptoms and side effects that are bothering me the most are [see page 4]:

- ☐ *These side effects are affecting my daily life in these ways:*
- ☐ *What can we do to manage these side effects?*

How likely is it that the cancer will return?

Is there a support group or social worker I can talk to about my experiences?

FINANCIAL RESOURCES

Even with a healthcare plan, treatment can be expensive. Keeping up with costs can be overwhelming. However, there are many resources that can help.

- Talk with your healthcare team and pharmacist about the cost of your treatment.
- Ask your doctor to refer you to an oncology social worker, financial counselor, or to a nonprofit organization for help managing financial issues and costs.
- Reach out to your healthcare plan to find out what resources they have that could help you.
- Ask about pharmaceutical assistance programs and what the qualification requirements are.
- If your treatment center is far away, ask if there are assistance programs that can help cover your travel costs.

To learn more about ways to manage the cost of treatment, visit: www.CancerSupportCommunity.org/Managing-Cost-Cancer-Treatment.

FINANCIAL SUPPORT RESOURCES

Cancer Support Community

888-793-9355

www.CancerSupportCommunity.org/Managing-Cost-Cancer-Treatment

Cancer Financial Assistance Coalition

www.CancerFAC.org

Patient Advocate Foundation

800-532-5274

www.PatientAdvocate.org

SKIN CANCER RESOURCES

Cancer Support Community

888-793-9355

www.CancerSupportCommunity.org/Squamous-Cell-Carcinoma

AIM At Skin Cancer Foundation

www.AIMatSkinCancer.org

CancerCare

800-813-4673

www.CancerCare.org

National Cancer Institute

800-422-6237

www.Cancer.gov

Skin Cancer Foundation

www.SkinCancer.org

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-Thurs 11am-8pm ET and Fri 11am-6pm ET.

Open to Options® — Preparing for your next appointment? 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.

Services at Local CSCs and Gilda's Clubs — With the help of 190 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.

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

MyLifeLine® — CSC's secure, online community welcomes anyone impacted by cancer to easily connect with community to reduce stress, anxiety, and isolation. Create a personal network site and invite friends & family to follow your journey. And participate in our discussion forums any time of day to meet others like you who understand what you are experiencing. Join now 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.

This publication is available to download and print yourself at www.CancerSupportCommunity.org/Skin-Cancer.

For print copies of this publication or other information about coping with cancer, visit Orders.CancerSupportCommunity.org

Frankly Speaking About Cancer: Non-Melanoma Skin Cancer Program Partner:



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