Talking about Basal 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 basal cell skin cancer. Inside this guide, you’ll find a quick overview of basal cell skin 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 BASAL CELL SKIN CANCER?

Basal cell skin cancer is the most common type of skin cancer. It starts in the top layer of the skin called the epidermis. Most basal cell skin cancers show up on sun-exposed areas of the body, especially the face and neck. But they can occur in other areas too. Basal cell skin cancer is often found early and can be cured. But sometimes it can grow back, and rarely it can spread to other parts of the body.

OVERVIEW OF TREATMENT FOR BASAL CELL SKIN CANCER

In most cases, basal cell skin cancer is easily cured using surgery or drugs applied to the skin (called topical therapies). Rarely, radiation is used. Treatment depends on where it is located, how big and deep the tumor is, and if lymph nodes are involved. Other treatment options are available for people with later stage disease.

<table>
<thead>
<tr>
<th>Stage</th>
<th>Description</th>
<th>Treatment Options</th>
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</thead>
<tbody>
<tr>
<td>Local, Low Risk BCC</td>
<td>Cancer is small and has not spread to other tissue</td>
<td>Surgery&lt;br&gt;• Excision – the entire growth is removed along with a surrounding border of normal skin&lt;br&gt;• Curettage and electrodesiccation – the tumor is scraped down to its base followed by pulses of electrical energy&lt;br&gt;Topical therapies – creams containing drugs can be applied to the skin</td>
</tr>
<tr>
<td>Local, High Risk BCC</td>
<td>Cancer has not spread to other tissue types but has high risk features such as: large area, itchiness or pain, or location on sensitive or sun-exposed skin</td>
<td>Mohs Surgery – removes skin cancer one layer at a time until normal, healthy tissue is reached&lt;br&gt;Chemotherapy – Uses drugs to kill fast-growing cells like cancer&lt;br&gt;Radiation therapy – uses high-powered energy beams to kill cancer cells and shrink tumors&lt;br&gt;Immunotherapy – strengthens the body’s immune system so it can fight cancer better&lt;br&gt;Targeted therapy drugs - keep cancer from growing and spreading with less harm to cells that are not cancer&lt;br&gt;Clinical trial – research studies that test new treatments</td>
</tr>
<tr>
<td>Advanced or Metastatic BCC</td>
<td>Cancer has spread aggressively in one area or spread to other parts of your body.</td>
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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 on what treatment plan is best for you and best fits your goals and preferences. Make sure you ask questions and discuss any concerns with your health care team.

If you have advanced BCC, 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.

For more information on stages of squamous cell skin cancer and treatment options, visit www.CancerSupportCommunity.org/basal-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.

- Ask if any clinical trials are right for you.

### 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 Basal 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.**

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

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.

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.

<table>
<thead>
<tr>
<th>Physical Health and Well-Being</th>
<th>What is most important for you to be able to do? What are your immediate concerns?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family and Social Relationships</td>
<td>Do you have support for your family and yourself?</td>
</tr>
<tr>
<td>Work/School</td>
<td>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?</td>
</tr>
<tr>
<td>Community/Involvement</td>
<td>Are you getting the support you need from your community? Are you able to stay active/involved in your community?</td>
</tr>
<tr>
<td>Other</td>
<td>What else is important to you?</td>
</tr>
</tbody>
</table>
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

- What type of biopsy or surgery am I having? ______________________________________________________
- How soon will I know the results? ______________________________________________________________
- How much of the skin/tissue will be taken? Will there be a lot of scarring? _________________________
- What is the plan if it is cancerous (malignant)? __________________________________________________
- What are the potential side effects of surgery? How will my appearance be affected? _________________
- What treatment is most likely to work? __________________________________________________________
- How likely is it that the cancer will return? ______________________________________________________
What should I be doing to prevent skin cancer from coming back? ______________________________
__________________________________________________________________________________

Do you work with a multidisciplinary team? If my skin cancer is advanced, 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? ______________________________
__________________________________________________________________________________

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

Basal Cell Skin Cancer Resources

Cancer Support Community • 888-793-9355 • www.CancerSupportCommunity.org/basal-cell-carcinoma
American Cancer Society • 800-227-2345 • http://bit.ly/ACSbsSkin
National Cancer Institute • 800-422-6237 • www.cancer.gov/types/skin
Skin Cancer Foundation • 212-725-5176 • www.skincancer.org/basal-cell-carcinoma

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 at 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 basal cell skin cancer 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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