FRANKLY SPEAKING ABOUT CANCER

Advanced Basal Cell Carcinoma

Advanced Basal Cell Carcinoma – What You Need to Know

Basal cell carcinoma (BCC) is the most common type of skin cancer. The majority of the time it is cured with local surgery, topical medications applied to the skin and/or radiation.

But in some cases, BCC can invade nearby tissue. When this happens, multiple surgeries may be needed to try to remove all of the cancer cells. These procedures can be disfiguring and very upsetting.

While BCC rarely spreads beyond the initial tumor site (roughly 1 in 6,000 cases), it can happen. Certain people are more likely to get BCCs, so it's particularly important that they get routine skin exams and follow up on anything that looks unusual.

For those with advanced or metastatic disease, dealing with the diagnosis can be very overwhelming. You may worry for your life, and how it will affect your ability to do certain things at home or work. It's important to learn about the disease, possible treatment options and ways to cope.

> *"Take one day at a time and continue to live a normal life as best you can."*
>
> *— Person living with advanced BCC*

CANCER SUPPORT COMMUNITY
A Global Network of Education and Hope

Support for Finding Facts about Advanced Basal Cell Carcinoma

Cancer Support Community	www.cancersupportcommunity.org
BCCNS Life Support Network	www.bccns.org
National Cancer Institute	www.cancer.gov
The Skin Cancer Foundation	www.skincancer.org

What is Basal Cell Carcinoma?

BCCs are abnormal, uncontrolled growths or lesions that arise in the skin's basal cells. Most BCCs occur on sun-exposed areas of the body; for example, on the head, face or neck. But they can occur in non-sun exposed areas, too.

Courtesy: Allan Halpern, M.D., Memorial Sloan-Kettering Cancer Center

Depending on the type of BCC (superficial, pigmented or nodular), these may appear like scaling pores, open sores, red patches, pink growths, shiny bumps, circular depression with raised irritated borders, or scars. Some patients say they noticed scrapes or growths on the skin that bled or never healed.

The problem is that what people see on the surface of the skin may only be the "tip of the iceberg," explains Dr. Parisa Momtaz of Memorial Sloan-Kettering Cancer Center. That's because BCC grows slowly and horizontally and deep under the skin. A biopsy is needed to confirm a diagnosis, and people with deep lesions often worry about whether surgeons "got it all."

> *"Even though basal cell carcinomas are considered to be relatively benign, they can be very serious. Their surgical removal can result in severe disfigurement. Left untreated, BCCs can progress to other structures and systems, for example, the lymph nodes, nerves, lungs or kidney."*
>
> *- Kristi Schmitt Burr, Executive Director, BCCNS Life Support Network*

BCC can spread or metastasize in rare cases. If BCC does spread, it is usually found in the lymph nodes, lungs, bone, skin and liver.

Some People Are Especially Prone to BCC

People who have a rare disorder called Basal Cell Carcinoma Nevus Syndrome (BCCNS), also called Nevoid Basal Cell Carcinoma Syndrome or Gorlin-Goltz Syndrome, are more likely to develop a few to thousands of BCC lesions because of a mutation or change in a specific gene called PATCH. They also tend to get BCCs at a younger age; some may appear even in childhood.

BCCNS is an inherited disorder. According to the Basal Cell Carcinoma Nevus Syndrome Life Support Network, nearly all individuals with this syndrome will develop multiple cancerous lesions over the course of their lives. BCC also tends to be more aggressive in people with this genetic mutation. Treatments are being developed to target this gene.

> *"I never thought that skin cancer could grow inward. It's pretty hard for people to understand that I have skin cancer in my lungs."*
>
> *- Person living with advanced BCC*

Getting Organized

Taking an active role in your care can help you along your journey. Here are some tips to consider:

- Learn as much as you can about your disease
- Make a list of your treatment options and the pros and cons of each
- Map out your goals for treatment
- Ask your health care provider about what the treatment will mean for your everyday life
- Talk to other people living with the disease
- Get a notebook or binder to keep copies of medical reports, track symptoms and side effects and to write down questions and concerns
- Work with your health care team to anticipate the next step if one treatment doesn't work
- Appoint a health care proxy and have a living will in place (this is a good idea regardless of your health)

Weighing Your Treatment Options

In its earlier stages, BCCs are often treated with surgery, topical therapies (used on the skin) and/or radiation. These therapies are often less effective in more aggressive lesions that have grown deep under the skin's surface to surrounding tissues.

Once BCC has metastasized (or learned to spread to other parts of the body), it becomes difficult to remove or destroy all sites of involvement.

Because many BCCs appear on the face, head or neck, surgical procedures can sometimes be challenging—the goal of surgery is to remove the lesion in its entirety while retaining function as well as an acceptable cosmetic outcome.

Figuring out the best treatments for late stage disease depends on a number of factors. These may include:

- **Where and how far the cancer has spread** (for example, is it still contained to one area, or has it spread beyond the skin and tissue to the muscle, nerves, lung or liver?)
- **How deep the tumor is**
- **If you have BCCNS or a personal history of BCC or other skin cancer**
- **Previous treatments tried** – some patients have already had extensive surgeries and can no longer undergo any more procedures because of how advanced the disease is locally, existing damage or because of other medical problems
- **Costs and practical considerations**
- **Your goals and preferences for treatment**

"Patients worry about the way it looks and feels and how it impacts their daily life. For example, for lesions on the face close to the nose or mouth, multiple surgeries may cause permanent cosmetic changes or affect their ability to eat."

— Dr. Parisa Momtaz, MSKCC

Treatment Options

Treatments for advanced BCC may be used alone or in combination.

Targeted Therapy

Just as it sounds, targeted therapy hones in on a specific protein or abnormal gene or cells.

Vismodegib (Erivedge®) works by blocking something called the hedgehog pathway. This pathway sends signals that tell cancer cells to grow. It is activated in most people with BCCNS. It is also found in one in three non-inherited mutations that occur randomly and for unknown reasons over the course of a person's life. Vismodegib is used in patients who can no longer have surgery, or who are at risk of losing the function of the facial feature (for example, their ear or nose); or when radiation is not an option. Other drugs that target the hedgehog pathway are also being studied.

Side effects may include muscle cramps, hair loss, weight loss, fatigue and loss of sense of taste.

Chemotherapy

For localized BCC, topical chemotherapy such as 5-flurouracil and imiquimod have shown clinical benefit.

For metastatic BCC, chemotherapy is given through the vein. This form of chemotherapy is treatment that kills cells that grow rapidly, one of the main properties of cancer cells. Since it is not "targeted" to BCC, other normal cells are affected too. Platinum-based chemotherapies have shown better clinical responses.

Common side effects are fatigue, nausea, hair loss and potential for infection, among others.

Radiation

Radiation therapy can be used in cases where surgery is challenging, or in older patients who are not candidates for surgery. Radiation therapy, however, may not be recommended for people with BCCNS because they are at higher risk of forming numerous new skin cancers after radiation exposure.

Palliative Care

Palliative care is a critical part of cancer care, regardless of what type of treatment you are getting. It can help with physical symptoms (for example, pain, fatigue), emotional stress, depression, and anxiety. Palliative care is appropriate at any point.

Clinical Trials

Clinical trials study new treatments or uses of existing medications to help treat cancer or make patients feel better. Ask your doctor if there are any clinical trials that might benefit you.

Monitoring Your Treatment

Your health care team will want to know how your treatment is working. This means you will have regular appointments and tests to monitor your health and to see what your tumor(s) is doing. If you have a new symptom, skin lesion or side effect in between visits, tell your doctor right away.

Questions to Ask

- What is the best treatment option for me?
- How will we know if it is working?
- What side effects should I be most concerned about?
- How do I explain my scars?
- Do my children need to be worried about BCC?
- Do I have BCCNS?
- What are the best strategies for sun protection?
- Am I going to lose function in my eye, nose, or ear?

"It is so important to stay on top of your health by becoming proactive in the diagnosis and treatment and to keep pushing for timely care. New therapeutics offer promise and hope for the future."

—Kristi, BCCNS survivor

Taking Steps to Cope

- **Learn about your diagnosis and what it means.**
- **Communicate with your health care providers often, and ask about how to manage your symptoms.** Pain is especially common.
- **Check your skin often.** Look over all of your skin surfaces including in between your toes, under your arms, etc.
- **Build a personal network of support.** This might include friends, family members, counselors, a patient navigator or other people living with the disease.
- **Remember beauty isn't only skin deep.** One patient offers this advice: "It's not the outside that counts, it's the inside." Repeated surgeries leave their mark.
- **Relieve stress and anxiety.** Try yoga, massage, going for walks, or other ways to relax.
- **Stay engaged in activities you enjoy or pick up a new hobby.**
- **Take care of yourself.** Get plenty of rest, eat nutritious foods, exercise and hydrate.
- **Stay sun safe.** Protect your skin by seeking the shade, limiting sun-exposure during peak hours (10 a.m.-3 p.m.), wearing sunglasses and sun hats, and applying sunscreen.

Other Considerations

There may come a time when cancer treatments are no longer working. Or you may decide you want to spend the time you have left in other ways. Hospice care provides comfort for people with advanced cancer who are no longer receiving treatment for their cancer. Hospice care is most commonly given by trained nurses in the comfort of your home. It is also offered in inpatient settings.

VALUABLE RESOURCES

Help is available to you and your loved ones. These resources can help you understand your treatment options, manage side effects, deal with emotions and connect with others impacted by metastatic melanoma.

CSC Resources for Support

Cancer Support Helpline® 888-793-9355
Our free helpline is open Monday – Friday 9:00 am – 8:00 pm ET. Anyone impacted by cancer can call to talk to a call center counselor. We will connect you with local and national resources, and help you find the right support.

OPEN TO OPTIONS®
Do you have questions about your cancer treatment? Open to Options® is a research-proven program that can help you prepare a list of questions to share with your health care team. In less than an hour, our Open to Options specialists can help you create a written list of specific questions about your concerns for your doctor.

Frankly Speaking About Cancer®
CSC's cancer education series, providing sound educational and psychological information for cancer patients and their loved ones.

Affiliate Network
Over 50 locations plus more than 100 satellites around the country offer on-site support groups, educational workshops, and healthy lifestyle programs specifically designed for people affected by cancer at no cost.

The Living Room, online
Through CSC's "The Living Room" you will find online support groups, discussion boards and social networking for patients and caregivers.

All of these services are made available with generous contributions from CSC supporters. **To access these services, visit www.cancersupportcommunity.org or call 1-888-793-9355.**

Help with Financial and Legal Concerns

Patient Advocate Foundation	800-532-5274	www.patientadvocate.org
		www.copays.org
Partnership for Prescription Assistance	877-477-2669	www.pparx.org

Other Resources and Support

The American Academy of Dermatology	www.aad.org
The Skin Cancer Foundation	www.skincancer.org
B.C.C. Nevus Syndrome Life Support Network	www.bccns.org

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