



FRANKLY SPEAKING **ABOUT CANCER**

A PROGRAM OF THE CANCER SUPPORT COMMUNITY



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SPOTLIGHT ON **ADVANCED NON-MELANOMA SKIN CANCERS**





If you have opened this book, it is likely that you recently learned that you or someone close to you has advanced non-melanoma skin cancer (NMSC). This may be a difficult and emotional time for you. You may have questions. This book aims to begin to answer some of those questions.

This book is specifically about ***advanced*** non-melanoma skin cancers. You may have already found that much of what is written about NMSCs relates to early-stage skin cancer. This book is different. While certain chapters relate to NMSCs broadly, most of the content focuses on the ins and outs of life with advanced NMSC.

There is a lot of information in these pages. It may be hard to take in all at once. Use this book as a resource and come back to it as you need.

We hope the information offered here can help you face tomorrow with knowledge and confidence to take the steps you need to go forward.

SPOTLIGHT ON

ADVANCED NON-MELANOMA SKIN CANCERS

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You Are Not Alone

A diagnosis of advanced cancer is usually unexpected, and almost always hard to hear. People with cancer describe feelings of sadness, worry, and fear. It is common to feel alone.

Advanced NMSCs are rare. Even people who know a little about skin cancer may not understand how they differ from early-stage skin cancers. Having a rare cancer or supporting someone with a rare cancer can bring its own challenges. You may have to work a little harder—to find the right doctor, to get support from friends, or to obtain the information you need to be an active member of your own health care team.

These 10 tips are a starting point. As you read them, think about how you can apply them to your own life. We hope that they will help you or your loved one feel more in control and better able to take an active role in this cancer journey.

1. **Take one step at a time and make one decision at a time.**

Life with advanced NMSC can feel overwhelming. Yet, with small steps you can find your

best path. Learn about NMSC by talking with doctors and patient navigators. Reach out to skin cancer organizations. Don't trust everything you read online. Ask all your questions. In time, you can collect the information and support you need to make good financial, medical, and personal decisions.

2. **Find a treatment team you trust.** Your treatment team includes the doctors, nurses, and other health care professionals who will provide care and support. It is important to find a knowledgeable treatment team you can trust. This means that you can talk openly with them and you believe that they can help. Try to get a second opinion from a doctor at an academic medical center or National Cancer Institute-approved cancer center. Ask about clinical trials that might be right for you. Treat this like an interview to find the best experts for the job. Your team should help you care for your mind, body, and spirit.



3. **Use a notebook to keep track of your diagnosis, symptoms, answers to questions, and next steps.** Be sure to write down the exact type of skin cancer you have. When you talk with your doctor, take notes or ask someone to help you take notes. You may hear new words. Ask your doctor to spell them out and define them. Write down this information and go back to it as needed.
4. **Accept help when it is offered. Day-to-day life and tasks can become harder.** Ask others for the help you want and need. Often, your friends and family will feel good offering assistance. An online scheduler can help you and your loved ones stay organized and informed. **MyLifeLine.org** is a tool that can connect your friends and family to the help you may need.
5. **Reach out to other people with advanced NMSC.** It's comforting to talk with others who understand what you're going through. People with advanced NMSC can also be a good source of knowledge. You and your loved ones don't have to feel lonely, helpless, confused, or hopeless. You can connect with others through the internet or a local support group. To find an in-person location near you for support, go to **CancerSupportCommunity.org/FindLocation**.
6. **Seek support from a patient advocate.** A trained advocate can help you navigate through many parts of the cancer journey. They can help manage insurance issues, find resources, and help with legal documents such as your will, medical directives, and estate plans. Many cancer centers offer, or can refer you to, a skilled advocate or patient navigator.
7. **Learn to relax and find a new perspective.** An advanced cancer diagnosis is life changing. Be aware of your feelings and how you handle them. Participate in activities that help you relax. Some examples of these include deep breathing, journaling, exercise, or creative activities. If you feel worried or depressed, consider talking with a social worker or therapist. You can learn to manage your feelings



and find a sense of calm. Take time to think about your life goals and self-image. Explore what's important to you and what makes you feel happy. Focus your energy on things that improve your well-being and provide happiness.

8. **Find ways to feel in charge of your life.** At times you may feel frustrated by changes to your work, school, and family life. Take action. Work with your medical team to come up with a plan that gives you as much control as possible over your treatment and care.
9. **Focus on nutrition and physical activity.** Every small step you take to eat better, move more, and find humor in life can make you feel better. Eating well will give you more energy and nutrients to help your body. You may feel tired but try to find times when you have energy to be active. Physical activity can lift your spirits, boost your energy, and reduce stress. Even when you feel tired, you can set reachable goals for healthy eating and physical activity (example: a 10-minute walk).

10. **Remember that hope is possible.** It may help to focus on family connections, cultural customs, and spiritual beliefs. If a cure is unlikely, hope can still make each new day better in some way. Plan to do something that makes you smile. Accept that some days will be better than others, but you can continue to enjoy the small, special moments.



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What Are Non-Melanoma Skin Cancers

Non-melanoma skin cancers begin in the top layer of the skin called the epidermis. There are many types of non-melanoma skin cancers. The three most common are basal cell carcinoma, cutaneous squamous cell carcinoma, and Merkel cell carcinoma. These cancers are often grouped together to differentiate them from melanoma, a skin cancer that forms and behaves in a different way. Skin cancers are named for the type of cell where they first form.

These cancers all begin with a mark, lesion, growth, or bump. It can vary in color, size, shape, and feel. Skin cancer is a solid tumor cancer. Even when the mark, lesion, growth, or bump is tiny, it is still considered a tumor.

TYPES OF NON-MELANOMA SKIN CANCERS

This book focuses on the three main types of non-melanoma skin cancer. These three cancers are distinct diseases, yet they share some characteristics, such as:

- The risk of developing NMSC is higher in people with fair skin or those who have spent a lot of time in the sun, used tanning beds, or had radiation treatment. Having a weakened immune system also increases risk.
- When they reach the advanced stage, these cancers are hard to treat. Treatment is likely to focus on keeping the cancer from growing and spreading, not cure.
- They are diagnosed and treated by the same kinds of doctors. The diagnosis process is similar for all, but treatment will vary by cancer type.

Basal cell carcinoma (BCC)- Basal cell carcinoma is the most common type of skin cancer. It accounts for around 8 out of 10 skin cancers diagnosed in the United States each year. This cancer starts in the basal cell layer or the lower part of the epidermis. The different subtypes of BCC can be classified as either indolent (slow-growing) or aggressive (fast-growing).



BCC can appear in a lot of different ways. It often begins as a small, shiny bump or a pink or red patch that develops into a sore that does not heal. This cancer is often found early and cured. It seldom reaches the advanced stage. People who develop basal cell cancers many times or more than twice at a young age may have basal cell nevus syndrome. This rare condition runs in families and increases the risk of BCC returning.

Squamous Cell Carcinoma of the skin or Cutaneous Squamous Cell Carcinoma (cSCC)- Squamous cell carcinoma of the skin is the second most common type of skin cancer. It is also called cutaneous squamous cell carcinoma so as not to confuse it with squamous cell carcinomas that affect other parts of the body. cSCC starts in the flat squamous cells in the outer layer of the skin.

The tumor may look like a firm red bump, a scaly red patch, an open sore, or a wart that may crust or bleed easily. Although it is usually found early and cured, this cancer is slightly more likely than basal cell carcinoma to reach the advanced stage. It is more common among people with weakened immune systems.

Merkel Cell Carcinoma (MCC)-

Merkel cell carcinoma is a very rare type of skin cancer. It begins in the Merkel cells. These cells are very close to nerve endings. They are found near hair follicles, among other places. This type of cancer often appears as a painless lump or bump on the skin anywhere on the body. It may be pink, red, or purple. It is more common in older people, especially those who were born male, and people with weakened immune systems.

Unlike BCC and cSCC, Merkel cell carcinoma is seldom found early. It tends to grow quickly and spread. It spreads first to nearby lymph nodes then to other parts of the body.

Merkel cell carcinoma is hard to treat after it spreads.

WHAT MAKES NON-MELANOMA SKIN CANCER ADVANCED?

Doctors use the word advanced to describe cancer that has grown and spread. This word is sometimes misunderstood. It can sound vague or general. In fact, a cancer has to meet certain medical criteria in order to be called advanced.

Advanced usually means that the cancer has grown deep into the skin, spread to another organ, or spread to



another part of the body. When cancer spreads, it often travels to the bones, brain, liver, or lungs. Non-melanoma skin cancers may also be considered advanced due to the:

- Size or depth of the lesion or tumor,
- Location of the cancer, or the
- Number of tumors on the body

Advanced means the same thing as stage 4.

DIAGNOSIS AND STAGING

Skin cancer is often found by a doctor during a skin exam. When cancer is advanced, a complete diagnosis usually takes more than one doctor's visit. It may involve a physical exam, scans, blood tests, and a biopsy. Your doctor will work with a team to figure out if you have skin cancer, the type, and where it has spread.

If you have a diagnosis of advanced NMSC, you probably had one of these four types of biopsies. Your doctor removed all or a sample of the tumor and sent the cells to a lab for a biopsy.

- **Shave Biopsy:** A doctor uses a sterile blade to shave off a growth that looks abnormal.

- **Punch Biopsy:** A special instrument is used to cut out circular pieces of skin or tissue.
- **Incisional Biopsy:** The doctor removes part of a growth using a scalpel.
- **Excisional Biopsy:** The doctor removes the entire growth or abnormal area of skin using a scalpel.

Your doctor also may have performed a **needle biopsy**. In a needle biopsy, a doctor removes fluid from the lymph nodes near the lesion. The fluid is sent to a lab for testing.

When a doctor suspects that cancer has spread, they use any or all of these scans to learn more:

Computerized tomography (CT) scan – This is a series of detailed pictures of areas inside the body. They are taken from different angles. The pictures are created by a computer linked to an x-ray machine. Also called CAT scan.

MRI (magnetic resonance imaging) – This scan uses radio waves and a powerful magnet linked to a computer to create detailed pictures of areas inside the body. These pictures can show the difference between normal and



diseased tissue. It is also called nuclear magnetic resonance imaging (NMRI).

PET scan – This scan uses radioactive glucose (sugar) to find cancer cells. The glucose is injected into a vein. Cancer cells use more glucose than normal cells, so they show up on the scan. This type of scan provides detailed, computerized images.

Ultrasound – This scan uses high-energy sound waves to look at tissues and organs inside the body.

X-Ray – This is a photograph of the inside of the body.

It is useful to know which tests and scans your doctor used to reach the diagnosis of advanced NMSC. If you are concerned that your doctor was not thorough, consider seeking a second opinion. Read more about how and when to pursue a second (or third) opinion in chapter 3.

STAGING

Staging is a key part of diagnosis. Doctors use the information they gather from blood tests, biopsies, and scans to get a full picture of the cancer. They assign a stage using the American Joint Committee on Cancer's TNM staging system. The

word “advanced” refers to the stage of cancer. The TNM system considers:

Tumor (T) – The size, location, and depth of the tumor or cancer lesion

Lymph nodes (N) – Whether cancer has spread to the lymph nodes near the tumor

Metastasis (M) – Whether cancer has spread to other parts of the body, like the bones, brain, liver, and lung

Each factor is assigned a number. The letter X is used for factors that cannot be measured. For example, a tumor could be T4, N3, and MX. The numbers are grouped to assign a stage, 0 through IV (4). Four means that the cancer has grown and spread the most. Advanced cancer is stage four.

Merkel cell carcinoma also uses substages. There is 0, IA, IB, IIA, IIB, IIC, IIIA, IIIB, and IV. Your doctor may describe the “pathological stage” or the “clinical stage.” The pathological stage takes into account all of the information gathered after some or all of the tumor is removed. A clinical stage may be given before surgery or if surgery is not possible.



NMSCs might be assigned a higher stage if they are on or near an important part of the body like the eye. The cancer also might be a higher stage if you have many cancerous marks.

You may hear other words doctors use to describe skin cancers, such as low risk, high risk, or advanced. They also sometimes say local, locally advanced, unresectable (meaning it can't be removed surgically), or metastatic to describe the stage. In order to understand your diagnosis as well as possible, we recommend that you ask your doctor for the numerical stage.



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Questions to ask about your diagnosis:

- What is the exact name of the kind of cancer I have?
- What is the type, subtype (if there is one), and stage?
- Where did the cancer start?
- Where is it located now?
- [If you had a prior cancer] Is this the same type of cancer I had before?
- Are there other biomarker tests, scans, or biopsies that should be done to help decide what treatment I should have?
- Do you have a suggestion for where to go or someone to see for a second opinion?



Treatment Planning

Treatment for advanced cancer of any kind usually involves a lot of doctor's appointments. You will get to know your health care team. You will work with your doctors to make decisions. Your nurses and patient navigators will support you as you manage side effects.

You are a partner in this process. Start to think of yourself as a member of your own health care team. It is important to find the right team for you.

FINDING THE RIGHT HEALTH CARE TEAM

You need a health care team you can trust. Aim to choose a doctor who is experienced with treating NMSC at the advanced stage. If possible, try to find a doctor who is connected to a National Cancer Institute-approved cancer center or a university hospital that conducts research. A doctor at a research hospital is likely to be part of a group or team that works together to treat people with advanced NMSC. Each doctor on the team brings specialized knowledge. For example, a medical oncologist or cancer doctor has special training in treating cancer

with drugs like chemotherapy, targeted therapy, or immunotherapy. At some cancer centers, the team discusses each patient at a group meeting. The doctors are likely to be up to date on the latest treatments.

The first step is to look for a doctor who has experience and expertise at treating exactly the kind of cancer you have. Here are some questions you can ask:

- How many advanced skin cancers of this type have you treated?
- How do you stay up to date on the latest treatments? (Look for someone who attends scientific meetings or reads medical journals.)
- Do you work with other specialists as part of a team?
- What other support services do you offer to people with advanced NMSC?
- Do you offer treatment through clinical trials?



Also consider practical matters like insurance and location. Ask where you will see them for regular appointments and for treatments. This may be the same location or two different ones.

It is sometimes more comfortable to choose the closest doctor or the first person you saw. Yet, every doctor does not offer the same treatments. With advanced cancer, where you go for health care makes a difference. Ask questions and interview doctors to make an informed choice.

GETTING A SECOND OPINION

Advanced non-melanoma skin cancers are rare. It may be harder to find a doctor who is experienced at treating them. If you are unsure of your doctor for this reason or for any reason, get a second opinion.

Many people with cancer get a second or even third opinion from another oncologist or cancer center. Some doctors even encourage it. Talking with other doctors can help you make a decision or confirm your current treatment plan. Another hospital or doctor may offer a different treatment or more useful support services. They may be a better fit for you in other ways. Do not worry about hurt feelings.

You can always return to the first doctor if you want.

A second opinion may:

- Help you feel more confident that you are getting the best possible care.
- Be especially helpful if one treatment stops working and you're looking for the next one to try.
- Give you some new options for treatment or management of side effects.

COMMUNICATING WITH YOUR TEAM

You've chosen your health care team. The next step is to make sure that you work with them in a way that is most helpful to you. Here are some tips for communicating with your health care team:

- Keep a running list of questions to bring to office visits.
- Bring a friend or family member to appointments to help listen and take notes.
- Ask about the best way to get your questions answered. Is it better to call, email, or bring a list to appointments?



Do you need to schedule an extra appointment if your list is very long?

- Find out who to contact with questions and concerns between visits. Write down their contact information.
- Ask questions until you are sure you understand. You deserve to get your questions answered in a way that makes sense to you. It's okay to ask the same question again. Tell your doctor if you need something described in a different language or format (e.g., a picture).

- Tell your team about:
 - Any side effects or symptoms
 - Any natural treatments you are taking. This includes herbs, vitamins, supplements, or other complementary treatments.
 - Medicines prescribed by any other doctor for other health conditions.
- Make sure your treatment goals are known and honored.

A patient navigator can also help you communicate with your health care team. Ask if your treatment center has patient navigators.



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KEY MEMBERS OF YOUR HEALTH CARE TEAM

Your health care team may include a:

Dermatologist - diagnoses and treats skin problems, including cancer.

Medical oncologist - diagnoses and treats cancer. Try to find one who specializes in skin cancers.

Primary care physician - still see this doctor for regular check-ups and non-cancer-related issues like diabetes, hypertension, or asthma.

Surgical oncologist - performs procedures to remove cancer tumors and cells.

Plastic surgeon - performs reconstruction if needed after skin cancer surgery.

Head and neck surgeon - performs procedures to diagnose and treat conditions in the head and neck area.

Mohs surgeon - performs a procedure where thin layers of skin are removed and looked at under a microscope. This process continues until no more cancer cells are left.

Pathologist - examines cells under a microscope for cancer, including during Mohs surgery.

Radiation oncologist - manages radiation treatments.

Radiologist - oversees the scans used to diagnose advanced skin cancer, including ultrasound, X-ray, MRI, CT scan, and PET scan.

Palliative care specialist - helps manage symptoms, pain, and side effects.

Oncology nurse practitioner (NP) or Oncology physician assistant (PA) - can diagnose and treat medical problems and prescribe medicine. They may see you with your doctor or independently. This may be the person you contact with urgent questions or concerns.

Oncology nurse - a registered nurse (RN) who specializes in cancer. Often, they administer treatments and other medicines. They can help you understand your cancer diagnosis and treatment. They can be a good source of information and support.

Oncology social worker - can provide counseling. They can also help you with financial, transportation, and home care needs.

Patient/nurse navigator - can help you talk with your health care team, help set up appointments, and help you get financial, legal, and social support.

Psychologist/psychiatrist - can provide mental health care to support you before, during, or after treatment. A psychiatrist can also prescribe medicine.

Nutritionist/registered dietitian - they can help find foods to eat or ways to eat them to get the nutrients you need. Look for a registered dietician (RDN) who has experience working with people with cancer.

Oncology Pharmacist - a pharmacist with special training in cancer medicines. They can teach you about drugs and how they interact. They can help you manage side effects. They also may help you find co-pay assistance or discounts.

Chaplain - can offer emotional and spiritual support. You also may find support from clergy outside of hospital.

Treatment Options for Advanced Non-Melanoma Skin Cancer

Treatment will likely involve surgery and drug therapy. The drug therapy might be targeted therapy, immunotherapy, or chemotherapy. Drugs may be used alone or together. Radiation therapy is sometimes used too. Creams and gels are often used to treat early-stage NMSCs. They are not a primary treatment for advanced non-melanoma skin cancers.

SURGERY

Treatment for non-melanoma skin cancers often begins with surgery. If possible, a doctor removes the primary tumor. The procedure may be performed in either a doctor's office or an operating room, depending on the approach used. Common procedures include:

- **Curettage and electrodesiccation or C and E** - This involves scraping the tumor down to the base.
- **Mohs surgery** - Mohs surgery is done in a doctor's office. It is done in phases to make sure that all the cancer cells are removed.

Each layer of skin is studied under a microscope before the next layer is removed.

- **Wide excision** - A wide excision is a cut done with a scalpel. The entire growth and surrounding border are removed. The removal of large lesions may require stretching skin or taking skin from other parts of the body to rebuild the affected area.
- **Lymph Node Dissection** - The procedure is performed in an operating room. Lymph nodes are removed. A sample of tissue is checked under a microscope for signs of cancer. There are two types—regional or radical. In a regional lymph node dissection, some of the lymph nodes in the tumor area are removed. In a radical lymph node dissection, most or all of the lymph nodes in the tumor area are removed. This procedure is also called lymphadenectomy.



- **Sentinel Lymph Node Biopsy -**

The sentinel node is the first lymph node that gets lymphatic drainage from the MCC tumor. It is removed during surgery and looked at under a microscope to check for cancer cells.

After surgery, you may notice pain or soreness in the area. Surgery also can result in numbness, scarring, or stretching of the skin. Care should be taken to prevent the wound from getting infected. If a large area of skin was removed, skin reconstruction or plastic surgery may be recommended. Ask about your options. Read more in Chapter 5 about skin stretching and scarring and how to encourage healing.

Scarring in a prominent place, like on the face, may cause distress. Talk with your health care team prior to surgery. Ask about what to expect. Seeking support from a cancer counselor or support group focused on skin cancer or head and neck cancer might be helpful.

TARGETED THERAPY

Targeted therapy aims to more precisely attack cancer cells. These drugs target changes in the genes or proteins of cancer cells that help them

grow, divide, and spread. They keep cancer from growing and spreading with less harm to cells that are not cancer.

Targeted therapy may be used to treat these advanced NMSCs:

Basal cell carcinoma – Drugs target the “hedgehog pathway” in the cancer cells. They block a signal in the cells that tells cancer to grow. These drugs are taken in pill form.

Squamous cell carcinoma – The FDA has not yet approved any targeted drugs to treat cSCC. Drugs may be available through clinical trials. One type of drug under study targets the EGFR biomarker. It is used to treat other cancers and has shown promise in early trials of cSCC.

IMMUNOTHERAPY

Immunotherapy uses the body’s natural defenses to find, attack, and kill cancer cells. It may help to think about it as boosting the immune system’s response.

Immunotherapy is often used to treat advanced squamous cell carcinoma and advanced Merkel cell carcinoma. It may be used to treat advanced basal cell carcinoma that does not respond to targeted therapy.



The drugs used to treat advanced NMCS are monoclonal antibodies. Monoclonal antibodies work by attaching to one substance on a cell, often a protein on a cancer cell. They then mark the cell as cancer, brings treatment to the cancer cell, or kills the cancer cell.

The drugs approved for advanced NMSCs belong to a group of drugs called checkpoint inhibitors. They work against the proteins PD-1 or PD-L1. These drugs are given through an IV to a vein. Different drugs in this group are approved for different NMSCs. Other drugs may be available through clinical trials.

CHEMOTHERAPY

Chemotherapy uses strong drugs to kill cancer cells anywhere in the body. It is given through an IV to a vein. Chemotherapy drugs in the form of a cream may be used on early-stage skin cancers.

Chemotherapy used to be the primary drug treatment for most types of cancer. As other types of drugs have become available, chemotherapy is used on its own less often. When it is used, it is sometimes combined with targeted therapy or immunotherapy.

Chemotherapy may be used to treat advanced Cutaneous Squamous Cell Carcinoma if immunotherapy is not working.

Common side effects of chemotherapy include diarrhea or constipation, fatigue, hair loss, mouth sores, nausea and vomiting, and increased risk of infection.

RADIATION THERAPY

Radiation therapy is the use of high-energy rays to kill or damage cancer cells. The goal is to damage as many cancer cells as possible without harming healthy tissue. To lessen damage, doses are very precise, and treatment is often spaced out.

The type of radiation therapy used to treat skin cancer is external beam. Radiation is given by a machine outside of the body.

With advanced NMSCs, radiation therapy may be used:

- Before, after, or at the same time as other treatments
- To ease symptoms
- To destroy tumors when surgery is not possible due to the location of the tumor or health of the patient



Radiation is not recommended for people who have basal cell nevus syndrome.

Common side effects include nausea, fatigue, and skin changes, such as redness, dryness, or itching at the site of treatment. Other side effects are specific to the part of the body being treated. Side effects can last after treatment is done.

CLINICAL TRIALS

Be sure to ask about clinical trials. Clinical trials are research studies to test new treatments or learn how to use existing treatments better. Today's standard treatments were developed in yesterday's clinical trials. Today's clinical trials may become tomorrow's standard treatments.

Key Things to Know about Clinical Trials:

- ☐ No one receives a placebo or "sugar pill" in place of appropriate treatments.
- ☐ Clinical trials test new treatments, new combinations of treatments, or better ways of using existing treatments.
- ☐ The U.S. Food and Drug Administration (FDA) and local review boards oversee all U.S. clinical trials to keep patients safe.
- ☐ If you join a clinical trial, you can leave at any time.
- ☐ Not every doctor offers the same trials.
- ☐ Often, the trial pays the costs of the drug being studied. Then, your health insurance and your copay cover "standard" treatment costs. Be sure to ask about the costs to you.
- ☐ There are phase I, II, and III clinical trials; make sure you understand the goals and risks of a clinical trial you join.
- ☐ Some clinical trials may make you ineligible for a future trial or treatment, so make sure to ask questions about this. See the resources below for help finding clinical trials that might be right for you.

In addition to talking with your doctor, you can look up clinical trials online if you know the type and stage of the cancer. Learn more here: [**www.CancerSupportCommunity.org/find-clinical-trial**](http://www.CancerSupportCommunity.org/find-clinical-trial)



PALLIATIVE CARE

Palliative care can help with symptoms or side effects. This care is not designed to treat the cancer itself. Instead, it will address symptoms caused by cancer or side effects from treatments.

You can receive palliative care at any time. The goal is to improve your quality of life. It is often provided by a specialist doctor or nurse. Many hospitals offer palliative care to people while they are receiving other treatments for cancer. Palliative care is not the same as hospice.



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POSSIBLE TREATMENTS BY CANCER TYPE	Surgery	Targeted Therapy	Immuno-therapy	Chemo-therapy	Radiation Therapy	Palliative Care	Clinical Trials
Advanced BCC	X	X	X		X	X	X
Advanced cSCC	X		X	X	X	X	X
Advanced Merkel cell carcinoma	X		X	X	X	X	X



Managing Symptoms and Side Effects

How you feel can affect your mood and outlook. It is hard to stay positive when you are tired, in pain, or uncomfortable. Managing symptoms and side effects can not only make you feel better physically but emotionally as well.

The first step to feeling better is to tell your health care team what is going on. Cancer treatments affect everyone differently. Your team won't know you are having a side effect or how much it interferes with your daily life unless you tell them.

Before you start treatment, ask what to expect. Is there anything you can do to prevent or prepare for this side effect?

When you notice side effects, tell your team right away. Be specific. Tell them what you notice, how often it occurs, how long it lasts, and if you have found anything that makes it better or worse.

You may reach a point where you feel like your concerns are not being heard. Or the suggestions or treatments are not working. If you have not already, ask to speak with a palliative care specialist. This health care professional focuses on symptom

management. Their goal is to improve the quality of life of people with serious illnesses. They may be able to offer tips and strategies you have not already tried.

Some common side effects and symptoms of advanced NMSC and its treatment include:

Constipation

Constipation occurs when you are unable to empty your bowels. It causes swelling, pain, and sometimes anxiety anticipating the pain. Ask your health care team if the drugs you are taking can cause constipation. There may be changes you can make or medicines to have on hand that can prevent or ease the impact of constipation. Do not take laxatives or stool softeners without talking to your doctor.

Drinking lots of fluids and walking, stretching, or yoga can help relieve symptoms. These food tips may be helpful as well:

- Choose high fiber foods, such as whole grains, fruits, vegetables, nuts, and beans.
- Try prunes and other dried fruits and juices, such as prune or apple juice.



- Drink hot beverages, such as herbal tea or decaffeinated coffee.
- If you are having gas and bloating, avoid “gassy” vegetables like cabbage, broccoli, cauliflower, peas, corn, or beans.

Diarrhea

Some drugs can irritate the lining of the stomach or intestines. This can cause diarrhea or watery stools. If this happens, try to stay hydrated. Carry a water bottle. Drink 8 to 10 glasses of fluid per day. Try water, sports drinks, broth, or other liquids that contain electrolytes. Avoid drinks with caffeine.

Changes to your diet may help too. Try to avoid a lot of spices, dairy, and fried foods. The BRAT (bananas, rice, applesauce, dry white toast) diet is recommended. Check with your doctor before using any over-the-counter anti-diarrheal medicines. Diarrhea can cause skin to become irritated or painful. Avoid this by keeping the rectal area clean and dry. Use A&D ointment to soothe and protect the skin.

When you need to go out, ask about restrooms in advance. Learn where they are located and, if possible, their condition. Travel with toilet paper and wipes if needed. Avoid situations where you may not be able to get to a bathroom easily. Carry an extra set of clothing when possible.

Fatigue

Fatigue is one of the most common experiences of people with cancer. Fatigue is a feeling of tiredness that does not always go away with rest. Fatigue can be caused by cancer treatment, or a symptom of the cancer itself. Talk with your health care team about fatigue.

Having less energy can interfere with your daily life. Consider these tips:

- Try to pay attention to when you have energy. Notice the times of day and how long your energy lasts. Plan activities, work, or chores for those times.
- Be active. Moving or exercising a little bit may give you more energy.
- Accept your limits. Fatigue can mean that you are not able to do as much for others. It can be hard to step back from activities or people who depend on you. Be honest with yourself and others.
- Let other people know what’s going on. Ask for help if needed.
- Build rest into your day.

Fever or flu-like symptoms

Cancer treatments can trigger an immune response. This may result in fever or flu-like symptoms. These side effects can lessen over time.



Talk with your health care team about how to manage them. Ask about over-the-counter drugs that are safe to take. Taking care of yourself may help you regain energy and feel better. Try to get enough rest, eat healthy foods, and stay active.

Infection

Cancer treatment can affect your blood counts and increase your risk of infection. Take care to avoid illness when possible. Try these tips:

- Wash your hands before and after eating, cooking, or going to the bathroom
- Get recommended vaccines
- Wash fruits and vegetables well
- Avoid crowds
- Be careful when cutting nails and brushing teeth
- Clean wounds
- Wear masks or gloves as needed

Talk with your health care team, household members, and caregivers about the ways they can help.

Hair thinning or hair loss

Hair loss is a possible side effect of both chemotherapy and some targeted drugs used to treat advanced NMSCs. Hair loss affects people in very personal ways. Some take it in stride while others care deeply about the change in appearance.

If hair thinning or hair loss is a possible side effect of the treatment you will receive, think about how you will feel. You have options. There are wigs, hats, and head coverings of all kinds. Going natural is an option as well. It has become more common to see people who have lost their hair due to cancer treatment walking around without anything on their heads.

When people know that hair loss is fairly certain, some choose to cut their hair or even shave their heads in anticipation. Others wait and see. Talk with your health care team about your preferences and how you can prepare.

Mouth sores

Mouth sores are a common side effect of chemotherapy and some other cancer treatments. They can cause general discomfort and interfere with eating.

There are no specific drugs to prevent mouth sores. There are medicines that can help relieve your discomfort.

It may help to keep the mouth moist and healthy through frequent rinsing with water or alcohol-free mouthwashes. Let your health care team know if sores are very painful or make it hard to eat or drink. Try these tips as well:

- Eat cold foods, such as popsicles, frozen fruit, and ice cream.



- Choose soft, bland foods that are easy to chew and won't irritate the mouth.
- Avoid:
 - Acidic or spicy foods, such as citrus fruits, tomatoes, peppers, and vinegar.
 - Crunchy or hard foods, such as crusty bread, pretzels, and chips.
 - Hot foods—choose room temperature or cold instead.
 - Alcohol and carbonated drinks.
- Other tips for mouth sores and mouth pain:
 - Suck on ice chips when you have mouth pain.
 - Drink through a straw to avoid sore spots.
 - Use a baking soda rinse before and after meals.

Muscle spasms or cramps

Muscle spasms and cramps are a common side effect of targeted therapy for advanced BCC and possibly other treatments. They can range in severity from a little bothersome to very painful.

If you know that the drugs you are taking may cause muscle spasms or cramps, take steps to prevent them. Try:

- Drinking a lot of liquids
- Stretching

- Avoiding sitting or standing for long periods of time
- Eating foods with vitamins and minerals that help retain electrolytes, such as bananas, sweet potatoes, spinach, and avocado

If you have muscle cramps, talk with your health care team about how to relieve them. They may suggest:

- Applying heat or ice
- Gently massaging the cramped area
- Light stretching or moving

Nausea and vomiting

Cancer treatment can cause stomach distress. It often comes in the form of nausea or vomiting. There are many drugs to treat nausea. Some are best used in advance to prevent nausea. Others may reduce nausea once it has started. Nausea can occur right after treatment or days later.

There are also natural approaches to managing nausea. Consider these tips:

- Try mindfulness, meditation, or relaxation exercises. These mind-body activities can help prevent nausea before and after treatment.
- Eat small meals and bland foods.
- Drink liquids.
- Drink or eat foods that might help like chamomile tea, ginger tea or gum, coconut water, or water.



If you have had nausea after treatment before, you may feel worry or dread in advance of the next treatment. In these situations, relaxation exercises may be helpful. If the feeling persists, ask your doctor about medicine to treat anxiety.

Pain (including joint pain)

Targeted therapy used to treat advanced NMSC can cause joint pain. Pain also may be a side effect of surgery. Pain can interfere with your sleep and your daily life. It can also affect your mood.

If you notice pain, take steps to manage it soon before it gets worse. Keep track of pain by taking notes on:

- when you notice it
- what it feels like
- how long it lasts
- how severe it is - Assign a number between one and 10 to describe the pain, with 10 being the worst pain.

Report this information to your health care team. Treatment may include pain medication, heat or ice, stretching, or massage. Sometimes physical therapy can be helpful.

Skin stretching or scarring

Surgery can result in skin stretching or scarring. Both can alter your appearance. Stretching can also cause discomfort.

It is hard to predict how skin will heal, and some of it is out of our control. However, there are things you can do to encourage less scarring and better healing, such as:

- Follow your health care team's instructions on how to care for the area after surgery. If you are not sure about something, call or email to ask.
- Apply moisturizer to the wound regularly.
- Limit movement or take care not to stretch the skin in the area.
- Avoid tobacco use or smoking.
- Drink fluids, especially water, and eat a healthy diet.
- Protect the area from the sun.
- Minimize stress.
- Be patient. Healing takes time.

If you are left with scars that make you uncomfortable, talk with a plastic surgeon. In some cases, reconstruction can help return skin to its prior appearance. Changes to your physical appearance, especially the face, can be upsetting. Seek support if needed.

Skin rash, dryness, or itching

Skin problems may be a side effect of immunotherapy, radiation therapy, other cancer treatments, or the cancer itself. You may notice rashes, itching, dryness, soreness, or burning.



Protect Your Skin from the Sun

Take care to avoid heavy sun exposure. Try these tips:

- ☐ Avoid being in the sun during peak daylight hours.
- ☐ Use sunscreen even when it's cloudy. Choose a product with broad spectrum coverage, SPF 15 or higher. Broad spectrum protects against UVA and UVB rays. Most sunscreens last 90 minutes when you are not in the water. They last less time if you are in the water. Reapply as needed, at least every two hours.
- ☐ Seek shade when possible.
- ☐ Wear protective clothing, including long sleeves or clothing with UV protection.
- ☐ Wear sunglasses. Look for ones that protect from UVA and UVB rays.
- ☐ Wear sun hats. Choose ones with wide brims that cover the neck and ears.

Some skin problems can be prevented. Talk with your health care about what to expect. Ask about topical treatments or products to keep on hand if you notice symptoms. Skin irritations often respond to treatment but it is best to treat early before symptoms get worse.

Try these tips:

- Clean skin with gentle soaps and pat dry
- Use fragrance-free moisturizers
- Try an oatmeal bath for itching
- Wear loose clothing
- Protect skin from the sun

Weight loss or decreased appetite

Many people with cancer lose or gain weight as a symptom of cancer or side effect of treatment. The drugs used to treat advanced NMSCs may lessen your appetite or lead to weight loss for other reasons. If you notice that you are eating less or losing weight, pay attention to what you are eating. Focus on healthy foods with fat or calories such as avocado, nuts and nut butters, salmon and other oily fish, meat, eggs, and dairy products.

A registered dietician at the cancer center or hospital may be able to help too. This person can advise on foods and eating behaviors that can help you maintain a healthy weight.



Coping with an Advanced Diagnosis

Learning that cancer is advanced can bring up a lot of emotions. Some days will be harder than others. Finding ways to take care of yourself can make a big difference in your life. Taking care of yourself means different things to different people. Most of us benefit from being active, eating well, getting enough rest, and making time for people and activities that bring us joy. Achieving this will be easier with support.

FINDING SUPPORT

Support can come in many forms. It can mean people who help you with tasks. It can also mean people or groups that provide emotional support. You may need different kinds of support at different times.

It is a good idea to line up support early on so that it is there when you need it. If you wait until the need is greater, it may be harder to find the energy to reach out.

Support may come from:

- Friends and family
- Therapists
- Social workers
- Support groups (online or in person)
- Helplines
- Religious counselors

Use the resources in this book to look for support. Find out what is available at your hospital or cancer center. The nurse, patient navigator, or social worker may be able to connect you with sources of support.

Support Groups

Support groups are not for everyone. Yet, many people with cancer find them to be a tremendous source of community, support, and information. They form friendships and share tips about their experiences with treatment, side effects, and more. If you look for a support group, try to find one that includes people with advanced skin cancer or other advanced cancer.



Practical Support

Start to think about people in your life who can provide practical support. These are people who might be able to help with childcare, pet care, meals, or chores. They might be able to give you rides or sit with you during an infusion. They might be your spouse or partner, adult children, friends, faith community, support group, or co-workers. Make a list of the specific ways each of them can help. Consider using **MyLifeLine.org** to help you stay organized and let friends know what you need.

Other Resources for Support

Ask your health care team about resources for social, emotional, physical, and practical support. If you search for information online, make sure that you use trusted websites. A list is provided at the end of this book. The Cancer Support Community and many of these organizations have helplines, online discussion boards, and more ways to seek support from others who have skin cancer.

Coping with Cancer-Related Distress

It is normal to feel stress, worry, or sadness. For some people, these feelings can become overwhelming. They stay with you, lasting for weeks at a time. They can make it difficult to do the things you need to do to take care of yourself or others.

This is described as cancer-related distress. If you think you may be experiencing distress, talk with your health care team. They may ask more questions in the form of a distress screening. Most importantly, ask them about resources for emotional support.

The Cancer Support Community's Cancer Support Helpline can answer questions and help you find resources. Call toll-free at 888-793-9355. The Helpline is available in 200 languages Monday through Friday from 9:00 am to 9:00 pm Eastern Time.



TAKING CARE OF YOUR BODY

Even as you focus on getting better, it is easy to neglect the basics of healthy living. Yet, taking care of your body can help you feel better. It can give you energy and improve your mood. As you are able, aim to:

- **Get enough rest** – Try to get enough rest. Take naps if needed. Talk with your health care team if pain or discomfort interferes with sleep. Visit www.CancerSupportCommunity.org/article/sleep-changes to learn more about how to cope with sleep problems.
- **Eat Healthy Foods** – What you eat can have a direct impact on how you feel. Healthy foods include protein, whole grains, vegetables, and fruit. If maintaining a healthy weight is hard, a dietician may be able to help. They can suggest ideas for foods and behaviors for nutrition and good health.
- **Be Active** – Moving your body can help you feel better. If you already exercise, you may need to adapt your workout to where you are now. If physical activity has not been a part of your life, now is a good time to start. Taking a walk or doing a little yoga or stretching can help your body and mind.

It can be hard to focus on all of these areas at once. Set reasonable goals, and seek support from family, friends, and your health care team in meeting them.

INSURANCE

Doctors seldom bring up insurance. Yet, the type of insurance you have and how much it covers can have a big impact on your experience.

If you have health insurance, take time to learn more about your policy. Call the insurance company to ask if your treatment is covered. Find out if there is a deductible that needs to be paid before insurance will pay. Ask about prescription drug coverage too.

If you do not have health insurance, talk with the social worker or financial counselor at the clinic or hospital. They can help you sign up for care. Depending on your age, health status, and income, you can obtain health insurance through Medicaid, Medicare, or the Affordable Care Act's Health Insurance Marketplace.



COPING WITH COST

Health care can be costly. Having cancer can affect your budget and any savings. Two important questions to ask about managing the cost of cancer care are:

- What financial impact will my cancer diagnosis and cancer treatment have on my life?
- Am I able to coordinate the financial piece of my cancer care right now?

Asking for and accepting help can also be hard. Families facing cancer have shared with the Cancer Support Community that financial worries about cancer costs are a significant source of stress, and they don't know where to turn. For more information to help you deal with costs related to your care, visit www.CancerSupportCommunity.org/Cost.

WORKING

It can be hard to juggle work and cancer treatment. This is especially true when cancer is advanced and treatment may be a part of life going forward. If you plan to continue working, be aware of these laws that protect people with cancer in the workforce.

The Americans with Disabilities Act (ADA) protects people with health problems such as cancer from discrimination. The ADA requires the workplace to make “reasonable accommodations” for anyone who is still able to perform the essential functions of the job. For example, your employer may allow flextime for doctors’ appointments. The ADA only applies to employers with 15 or more employees.

The Family and Medical Leave Act (FMLA) applies to companies with 50 or more employees. It allows you (the person with cancer) and your family members to take up to 12 weeks of unpaid leave with health insurance. There is also intermittent FMLA for people with chronic health conditions. This allows you to take more days off for treatment or doctors’ appointments. Your job will be protected.

Vocational Rehabilitation Act of 1973 helps people with cancer who need to find a different kind of job. This act ensures that they can get job retraining. State government agencies can help with this process.



The government agency that oversees these laws is the **Equal Employment Opportunity Commission (EEOC)**. If you have any questions about workplace laws, they have a toll-free number that many people find very helpful: 800-669-4000.

COPING FOR CAREGIVERS

A caregiver is anyone who provides support to a person with cancer. Support can come in many forms. It may be emotional, like being a good listener. Or it may be practical, like helping with chores or doctors' appointments. A caregiver can live with the person, nearby, or far away.

You may have volunteered to be a key support to the person, or the responsibility may have fallen on you. However you got here, recognize that you play an important role in your loved one's life. It is easy for caregivers to become so focused on that role that they neglect their own physical or mental health. In order to have energy for caregiving, you need to take care of yourself too. This may mean:

- Taking breaks
- Paying attention to your own health
- Eating right
- Staying active
- Building in time for things that bring you joy or help you relax



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Advanced Care Planning and Hospice

Learning you have cancer can change the way you think about things. You may make different choices than you did before. It is common to think more about death, your own or that of your loved one. This can have a positive or negative impact, or both. You may recognize what and who is most important to you and make time for it or them. It also can become a source of worry and sadness.

Some people with advanced skin cancer live for many years. The cancer responds well to treatment. The rapid pace of cancer research means that there are often new treatments to try. Yet, there may come a time treatment stops working.

Preparing for that time now can help you feel more in control. As you look toward the future, you can take steps to feel more comfortable. Some of these steps can be taken in advance.

GET YOUR PAPERS IN ORDER

One of the ways to feel more in control of life is to make sure that your legal documents are in order. These documents are recommended for everyone, even healthy, young people. If you have prepared them before,

revisit them to see if you want to make any changes. If you have not, reach out to a lawyer or use online resources to do so now. Aim to make a:

Will – a document that plans for the distribution of your property and money. You will be asked to identify legal guardians for your children under the age of 18. You also may need to make plans for your pets. The executor of your estate is a trusted person you appoint to help carry out your wishes.

Living will or advanced directive – a document that details your wishes about medical treatment if a time should come when you can no longer say what you want. Most states honor a living will prepared in advance. However, the laws vary by state.

Health care proxy or medical power of attorney – a document that allows you to name a trusted person to make decisions about your medical care if you cannot do so yourself. In many states, this person is authorized to speak for you any time you are unable to make your own medical decisions, not only at the end of life.



Financial power of attorney – this document names a trusted person who is able to make financial decisions and payments for your health care needs if you are unable to do so yourself. You may want to name two different people as your medical and financial power of attorney. This can ensure that there are no potential conflicts of interest when decisions about your care need to be made.

Do Not Resuscitate (DNR) Order – an order that your doctor writes on your chart if you do not want “heroic measures” taken in the event of a cardiac or respiratory arrest. This is used if you stop breathing or your heart stops working and you aren’t revived right away. The order says that you do not want to be put on machines that will keep your body alive even though you’re unconscious. It is very important to think about this issue and discuss it with your family and doctor before you get seriously ill.

Out of hospital DNR – This DNR serves the same purpose as the one above but you keep copies of it. It can be provided to emergency services workers. States have different laws around this. Look into the laws of the state(s) where you live and spend the most time.

REACH OUT TO PEOPLE OR SEEK CLOSURE

As you start to think about your life, you may feel like you have loose ends or unfinished business. You may want to let friends or loved ones know how you feel about them. You may have stories to tell. These feelings are important to recognize and act on. Some people find meaning in:

- Reaching out to people they haven’t seen or talked to in a while. You can do this by phone or video call, email, text, or letter.
- Writing letters or recording messages to be shared with loved ones after they are gone. For example, you prepare a letter or video to be shared with children or grandchildren at a special moment in life like at a graduation or on a wedding day.
- Telling their stories. Our lives are unique. We all have stories to tell. They may involve celebrating accomplishments, describing experiences, or explaining mistakes. Some people find purpose in talking or writing about their lives. There are apps and websites designed to make this easier.



LEARN ABOUT HOSPICE

Hospice can provide care and comfort to people affected by cancer at the end-of-life. Hospice care is provided by a trained nurse or health care worker. Care can be provided in your home. It can also take place at a hospice facility. A hospice team is available to meet your physical and emotional needs, as well as the emotional needs of your family.

Ask your health care team about hospice early in your treatment. Find out when and how hospice may be a useful part of your care. Many people are referred to hospice later than they could be. This means that they and their families miss the opportunity to benefit from everything hospice has to offer.

MAINTAIN HOPE

Hope does not always come easily. It may be within grasp on some days yet feel unattainable on others. Yet, hope can give you strength to face what's next. Hope can help you find joy in small moments and loved ones.

Try to find things to look forward to. They may be small like the next episode of a gripping television show or the magic of a blooming plant in your garden. Or you may look forward to big events like a family reunion or a work party. Look around you for sources of hope. Never be afraid to hope, knowing that what you hope for may change over time.



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NON-MELANOMA SKIN CANCER INFORMATION AND SUPPORT

American Cancer Society of Clinical Oncology • 888-282-2552 • www.asco.org

CancerCare • 800-813-4673 • www.CancerCare.org

National Institute of Health's Clinical Trial Search • ClinicalTrials.gov

Skin Cancer Foundation • www.SkinCancer.org

Merkelcell.org • www.Merkelcell.org

American Academy of Dermatology Association • www.aad.org/public/diseases/skin-cancer/types

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

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

National Comprehensive Cancer Network • 215-690-0300 • www.nccn.org/patientresources/patient-resources/guidelines-for-patients

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 and Sat-Sun 9am-5pm 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. 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.

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. 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.

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



SO THAT NO ONE FACES CANCER ALONE®

As the largest professionally led nonprofit network of cancer support worldwide, the Cancer Support Community (CSC), including its Gilda's Club affiliates, is dedicated to ensuring that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community. CSC achieves its mission through three areas: direct service delivery, research, and advocacy. The organization includes an international network of Affiliates that offer the highest quality social and emotional support for people impacted by cancer, as well as a community of support available online and over the phone. The Research and Training Institute conducts cutting-edge psychosocial, behavioral, and survivorship research. CSC furthers its focus on patient advocacy through its Cancer Policy Institute, informing public policy in Washington, D.C., and across the nation.

**For more information, visit www.CancerSupportCommunity.org
or call the toll-free Cancer Support Helpline at 888-793-9355**

The Cancer Support Community and its partners provide 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.

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