

Advanced Basal Cell Carcinoma

Complete discussion guide

A printable set of questions to bring to appointments with your care team. Each section below is also available as its own one-page checklist.

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<https://www.beatingskincancer.com/basal-cell-carcinoma/advanced-bcc>



What Advanced BCC Means

Advanced Basal Cell Carcinoma

<https://www.beatingskincancer.com/basal-cell-carcinoma/advanced-bcc/what-advanced-bcc-means>

Appointment date

Doctor's name

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- ☐ Is my BCC locally advanced, or has it actually spread? What did the imaging show?
 - ☐ Why can't this be treated with surgery or radiation — is that permanent, or could it change?
 - ☐ Will my case be reviewed by a multidisciplinary team?
 - ☐ What systemic treatment would you start with, and what is the goal — cure, control, or shrinking it before surgery?
 - ☐ How will we know whether the treatment is working?
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The Multidisciplinary Workup

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<https://www.beatingskincancer.com/basal-cell-carcinoma/advanced-bcc/multidisciplinary-workup>

Appointment date

Doctor's name

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- ☐ Based on the exam and pathology, how far do you think this tumor extends — and do we need a scan to be sure?
 - ☐ Is there any sign the cancer is involving a nerve?
 - ☐ Which subtype is on my pathology report, and does it change the plan?
 - ☐ Which specialists will be involved in my care, and who is coordinating it?
 - ☐ Will my case be presented at a tumor board? When will I hear the recommendation?
 - ☐ Is my tumor still removable with surgery, or are we considering other treatments first?
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When Surgery and Radiation Are Not Enough

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<https://www.beatingskincancer.com/basal-cell-carcinoma/advanced-bcc/when-surgery-radiation-not-enough>

Appointment date

Doctor's name

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- ☐ Why specifically is surgery not an option for my tumor — location, size, prior operations, or my overall health?

 - ☐ Has radiation been ruled out, and if so, why?

 - ☐ Could medication shrink this tumor enough to make surgery possible later?

 - ☐ Will my case be presented at a multidisciplinary tumor board?

 - ☐ If we start systemic treatment, what is the goal, and how will we measure whether it is working?



Hedgehog Pathway Inhibitors

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<https://www.beatingskincancer.com/basal-cell-carcinoma/advanced-bcc/hedgehog-pathway-inhibitors>

Appointment date

Doctor's name

- ☐ Is my BCC locally advanced or metastatic, and which hedgehog inhibitor do you recommend for me and why?

- ☐ What response is realistic for a tumor like mine, and how will we measure whether it is working?

- ☐ How long might I need to take it, and what would make us stop or switch?

- ☐ What side effects should I expect, and what is the plan for managing them or taking breaks?

- ☐ If the drug stops working, what are my next options — immunotherapy or a trial?

- ☐ What contraception and blood-donation precautions apply, and for how long after the last dose?



Managing Hedgehog Inhibitor Side Effects

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<https://www.beatingskincancer.com/basal-cell-carcinoma/advanced-bcc/managing-hedgehog-inhibitor-side-effects>

Appointment date

Doctor's name

- ☐ Which side effects am I most likely to get, and when might they start?

- ☐ What specifically can we do about muscle cramps and taste changes?

- ☐ At what point would we lower the dose or take a break — and can we plan breaks in advance?

- ☐ If I stop for a few weeks, is there a risk the cancer comes back or stops responding?

- ☐ Should I see a dietitian, and do you recommend any supplements?

- ☐ Which symptoms mean I should call you right away rather than wait for my next visit?



Immunotherapy for Advanced BCC

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<https://www.beatingskincancer.com/basal-cell-carcinoma/advanced-bcc/immunotherapy-for-advanced-bcc>

Appointment date

Doctor's name

☐ Is immunotherapy the right next step for me, or are other options still on the table?

☐ Given my tumor, what is a realistic chance that it will shrink on cemiplimab?

☐ What immune-related side effects should prompt me to call you right away?

☐ How will we know if it is working, and how long before we can tell?

☐ Do my other medical conditions or medications raise my risk with this drug?

☐ Is there a clinical trial I should consider instead of or alongside this?



Neoadjuvant Therapy Before Surgery

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<https://www.beatingskincancer.com/basal-cell-carcinoma/advanced-bcc/neoadjuvant-therapy-before-surgery>

Appointment date

Doctor's name

- ☐ What would surgery look like now, and how might it change if the tumor shrinks first?

- ☐ How many months of medication are you planning, and how will we measure the response?

- ☐ What side effects are most likely, and at what point would we stop early?

- ☐ How will you find and remove the original tumor border after it shrinks?

- ☐ Is a clinical trial of neoadjuvant treatment an option for me?

- ☐ Will my insurance cover this use of the drug?

Clinical Trials for Advanced BCC

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<https://www.beatingskincancer.com/basal-cell-carcinoma/advanced-bcc/clinical-trials-for-advanced-bcc>

Appointment date

Doctor's name

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- ☐ Is there a clinical trial that fits my specific type of advanced BCC and my treatment history?

 - ☐ What phase is it, and how much is already known about the study drug's safety and benefit?

 - ☐ Would the trial replace my standard treatment, add to it, or be a next step if my current drug stops working?

 - ☐ What extra visits, scans, biopsies, or travel would it involve compared with standard care?

 - ☐ What are the known and possible side effects, and how would they be monitored?

 - ☐ What happens if the trial treatment does not work for me, or if I decide to stop?

 - ☐ Which costs are covered by the sponsor, and what would my insurance still be billed for?



Gorlin Syndrome

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<https://www.beatingskincancer.com/basal-cell-carcinoma/advanced-bcc/gorlin-syndrome>

Appointment date

Doctor's name

- ☐ Do my features meet the criteria for Gorlin syndrome, and should I have genetic testing and counseling?

- ☐ Should my children or other relatives be tested or screened, and starting at what age?

- ☐ How often should I have skin exams and jaw imaging?

- ☐ Which of my BCCs can be managed with creams, light therapy, or curettage rather than surgery?

- ☐ Am I a candidate for a hedgehog pathway inhibitor, and would it be a short course or longer term?

- ☐ Given my radiation sensitivity, how should imaging and any future radiotherapy be handled?

- ☐ Are there clinical trials or specialty clinics for Gorlin syndrome I should know about?

Questions to Ask Your Care Team About Advanced BCC

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<https://www.beatingskincancer.com/basal-cell-carcinoma/advanced-bcc/questions-to-ask-your-care-team>

Appointment date

Doctor's name

Questions About Your Diagnosis and Testing

- ☐ What does "advanced" mean in my case — is this locally advanced or metastatic disease?

- ☐ Which subtype of BCC is on my pathology report, and is it an aggressive one?

- ☐ Is there any sign the tumor is growing along a nerve (perineural invasion)?

- ☐ Do I need an MRI, CT, or other scan before we decide on treatment? Why or why not?

- ☐ Has my tissue been reviewed by a dermatopathologist here, or should the slides be re-reviewed?

- ☐ Should I be checked for Gorlin syndrome or another reason I am getting these tumors?

- ☐ Will my case be presented at a tumor board, and when will I hear the recommendation?

Questions for Your Dermatologist or Mohs Surgeon

- ☐ Is my tumor still removable with surgery, or has it reached the point where surgery and radiation are no longer enough?

- ☐ If it is removable, what technique would you use, and what is the expected cure rate?

- ☐ How large would the wound be, and who would handle the reconstruction?

- ☐ What structures are near the tumor that could be affected — nerves, the eye, cartilage, bone?

- ☐ Would treatment before surgery to shrink the tumor make the operation smaller or safer?



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- ☐ Who is coordinating my overall care, and how do I reach that office between visits?
 - ☐ Would you recommend a second opinion at a center that treats many advanced skin cancers?
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Questions for Your Surgeon

For a head and neck or surgical oncologist planning a larger operation:

- ☐ What exactly would be removed, and how would that affect how I look, speak, chew, or see?
 - ☐ How likely is it that you will get clear margins in one operation? What if you do not?
 - ☐ Will lymph nodes be removed or sampled?
 - ☐ What is the recovery like — hospital stay, time off, drains, wound care?
 - ☐ Is radiation or medication likely to be recommended after surgery?
 - ☐ How many operations like this do you and this center do each year?
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Questions for Your Radiation Oncologist

- ☐ Is radiation the main treatment here, or is it being added after surgery?
 - ☐ How many sessions, over how many weeks, and what does a session involve?
 - ☐ What are the short-term effects (skin irritation, fatigue) and the long-term ones for my treatment area?
 - ☐ Do I need a dental evaluation or other preparation before starting?
 - ☐ What is the chance radiation controls the tumor long term, given its size and location?
 - ☐ Can this area be treated again later if the cancer comes back?
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Questions for Your Medical Oncologist

When systemic (whole-body) medication is on the table:



- ☐ Are we starting with a hedgehog pathway inhibitor, immunotherapy, or a clinical trial — and why that one first?

- ☐ Is the goal to shrink the tumor before surgery, or to control it long term?

- ☐ What side effects are most common, and how are they managed? Which ones should prompt me to call?

- ☐ How and when will we know if the medication is working? What scans or exams, how often?

- ☐ Are treatment breaks an option if side effects build up?

- ☐ What is the plan if this drug stops working or I cannot tolerate it?

- ☐ Is there a clinical trial I should consider, here or elsewhere?

- ☐ Do I need to avoid pregnancy or fathering a child during and after this treatment?

Questions About Daily Life, Support, and Cost

- ☐ How will treatment affect my ability to work, drive, and care for my family?

- ☐ Is there a nurse navigator or social worker who can help with scheduling, transportation, and paperwork?

- ☐ What will this cost me, and is there financial assistance or a copay program for the medication?

- ☐ What support is available for the emotional side — counseling, support groups, palliative care for symptom relief?

- ☐ Who do I call after hours if I have a problem related to treatment?

- ☐ What does follow-up look like once active treatment ends?

Questions to Prioritize If Your Time Is Short

If you can only ask a handful, start here:

- ☐ Is the goal of treatment to cure this or to control it?

- ☐ Can the tumor still be removed with surgery?

- ☐ What are my treatment options, and which do you recommend and why?

- ☐ What are the main side effects, and how reversible are they?

- ☐ Has a multidisciplinary team reviewed my case?

- ☐ Who is my main point of contact, and how do I reach them?

Living With Advanced BCC

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<https://www.beatingskincancer.com/basal-cell-carcinoma/advanced-bcc/living-with-advanced-bcc>

Appointment date

Doctor's name

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- ☐ Is my BCC locally advanced or metastatic, and what does that mean for my outlook?

 - ☐ What is the goal of my treatment right now — to cure, to shrink the tumor, or to control it long term?

 - ☐ What will my follow-up schedule and imaging look like over the next year?

 - ☐ If long-term side effects become hard to live with, what are my options — dose changes, treatment breaks, or switching therapy?

 - ☐ Can you refer me for reconstruction or a prosthesis, and when would that happen?

 - ☐ Can I meet with a palliative (supportive) care team, and how do I connect with a social worker?

 - ☐ What support is available for my caregiver?
