

# Advanced Squamous 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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### Sections

1. What Advanced SCC Means
2. High-Risk Features
3. The Multidisciplinary Workup
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5. Nodal Metastasis and the Sentinel Node
6. When Surgery and Radiation Are Not Enough
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<https://www.beatingskincancer.com/squamous-cell-carcinoma/advanced-scc>



## What Advanced SCC Means

Advanced Squamous Cell Carcinoma

<https://www.beatingskincancer.com/squamous-cell-carcinoma/advanced-scc/what-advanced-scc-means>

Appointment date

Doctor's name

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- ☐ Is my SCC locally advanced, or has it actually spread? What did the imaging show?

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- ☐ Why can't this be treated with surgery or radiation — is that permanent, or could it change?

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- ☐ Will my case be reviewed by a multidisciplinary team?

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- ☐ What systemic treatment would you start with, and what is the goal — cure, control, or shrinking the tumor before surgery?

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- ☐ How will we know whether the treatment is working, and how often will I be scanned?

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## High-Risk Features

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<https://www.beatingskincancer.com/squamous-cell-carcinoma/advanced-scc/high-risk-features>

Appointment date

Doctor's name

- ☐ Which specific high-risk features does my tumor have, and what does my pathology report say about depth, differentiation, and perineural invasion?  
\_\_\_\_\_
- ☐ What is my tumor's stage in the AJCC and BWH systems, and my NCCN risk category?  
\_\_\_\_\_
- ☐ Does my risk level call for Mohs surgery, wider margins, or radiation after surgery?  
\_\_\_\_\_
- ☐ Do I need imaging or a sentinel lymph node biopsy to check my lymph nodes?  
\_\_\_\_\_
- ☐ How often should I be seen for follow-up, and what should I watch for between visits?  
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## The Multidisciplinary Workup

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<https://www.beatingskincancer.com/squamous-cell-carcinoma/advanced-scc/multidisciplinary-workup>

Appointment date

Doctor's name

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- ☐ Has a dermatopathologist re-reviewed my slides, and does the report list differentiation, depth, perineural and lymphovascular invasion, margins, and subtype?

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- ☐ What is my stage under the BWH and AJCC8 systems, and what does that predict?

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- ☐ Do I need a scan — and should it be CT, MRI, PET-CT, or ultrasound?

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- ☐ Is there any sign the cancer has reached a nerve or a lymph node?

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- ☐ Which specialists will be involved, and will my case go to a tumor board?

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- ☐ Are there clinical trials I should consider now, before we start treatment?

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## Perineural Invasion

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<https://www.beatingskincancer.com/squamous-cell-carcinoma/advanced-scc/perineural-invasion>

Appointment date

Doctor's name

☐ Is my perineural invasion incidental (microscopic) or clinical, and what size nerve is involved?

☐ Was a named nerve involved, and were my surgical margins clear of nerve?

☐ Do I need an MRI, and what did it show about the nerve and the skull base?

☐ Does the PNI change my stage under the AJCC or BWH systems?

☐ Do you recommend radiation after surgery? Why or why not, and what area would it cover?

☐ What symptoms should prompt me to call, and how often will I be seen for follow-up?



## Nodal Metastasis and the Sentinel Node

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<https://www.beatingskincancer.com/squamous-cell-carcinoma/advanced-scc/nodal-metastasis-and-sentinel-node>

Appointment date

Doctor's name

- ☐ Based on my tumor's features and stage, what is my estimated risk of spread to lymph nodes?  
\_\_\_\_\_
- ☐ Which lymph node basin drains my tumor, and how will it be checked and followed?  
\_\_\_\_\_
- ☐ Do you recommend a sentinel lymph node biopsy in my case? What are the pros and cons for me?  
\_\_\_\_\_
- ☐ If a node is involved, would you recommend surgery, radiation, or both — and would systemic therapy be added?  
\_\_\_\_\_
- ☐ Was extranodal extension present, and how does that change my treatment?  
\_\_\_\_\_
- ☐ How often will I have exams and imaging, and for how long?  
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## When Surgery and Radiation Are Not Enough

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

Appointment date

Doctor's name

- ☐ Why specifically is surgery not an option — location, extent, prior operations, or my overall health?  
\_\_\_\_\_
- ☐ Has radiation been ruled out, and if so, why — have I already had radiation to this area?  
\_\_\_\_\_
- ☐ Could immunotherapy shrink this tumor enough to make surgery possible later?  
\_\_\_\_\_
- ☐ Will my case be presented at a multidisciplinary tumor board?  
\_\_\_\_\_
- ☐ Is the goal of treatment to cure the cancer, to control it, or to relieve symptoms?  
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- ☐ If we start systemic therapy, how will we measure whether it is working?  
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## Immunotherapy for Advanced SCC

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<https://www.beatingskincancer.com/squamous-cell-carcinoma/advanced-scc/immunotherapy-for-advanced-scc>

Appointment date

Doctor's name

- ☐ Is my SCC locally advanced or metastatic, and is immunotherapy the right first step?  
\_\_\_\_\_
- ☐ Would you use cemiplimab or pembrolizumab for me, and why?  
\_\_\_\_\_
- ☐ Given my tumor, what is a realistic chance it will shrink, and how long until we know?  
\_\_\_\_\_
- ☐ Do I have any condition — a transplant, an autoimmune disease — that raises my risk with this treatment?  
\_\_\_\_\_
- ☐ How often will I have scans and blood tests, and how long would I stay on treatment?  
\_\_\_\_\_
- ☐ If it does not work or stops working, what would we do next? Is there a clinical trial for me?  
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## Managing Immunotherapy Side Effects

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<https://www.beatingskincancer.com/squamous-cell-carcinoma/advanced-scc/managing-immunotherapy-side-effects>

Appointment date

Doctor's name

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- ☐ Which side effects are most likely for me, and which are the dangerous ones to watch for?  

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  - ☐ What blood tests will you run before each infusion, and what are you looking for?  

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  - ☐ At what point would we pause treatment, and at what point would we stop it for good?  

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  - ☐ If I need steroids, how long would that last, and what else do I need while taking them?  

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  - ☐ If I develop a thyroid or other hormone problem, can I stay on immunotherapy?  

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  - ☐ Who do I call after hours, and what symptoms should send me straight to the emergency room?  

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## Neoadjuvant Immunotherapy Before Surgery

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<https://www.beatingskincancer.com/squamous-cell-carcinoma/advanced-scc/neoadjuvant-immunotherapy-before-surgery>

Appointment date

Doctor's name

- ☐ Is my tumor a candidate for immunotherapy before surgery, and what would that change about my operation?  
\_\_\_\_\_
- ☐ How many doses would I get, and how long before we know whether it's working?  
\_\_\_\_\_
- ☐ Will I still need surgery even if the tumor seems to disappear?  
\_\_\_\_\_
- ☐ What happens to the surgical plan if the tumor doesn't shrink, or grows, during treatment?  
\_\_\_\_\_
- ☐ Is a transplant, autoimmune condition, or other health issue a reason to avoid this approach for me?  
\_\_\_\_\_
- ☐ Who is on my team for this — dermatology, surgery, and medical oncology together?  
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## Chemotherapy and EGFR-Targeted Therapy

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<https://www.beatingskincancer.com/squamous-cell-carcinoma/advanced-scc/chemotherapy-and-egfr-targeted-therapy>

Appointment date

Doctor's name

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- ☐ Why is cetuximab or chemotherapy being recommended for me instead of immunotherapy?

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  - ☐ Is this because of a transplant, immunosuppression, an autoimmune condition, or because immunotherapy already stopped working?

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  - ☐ What response rate is realistic for my specific situation?

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  - ☐ What side effects should I expect, and how will they be managed — for cetuximab's rash, or chemotherapy's effect on blood counts?

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  - ☐ Would combining this with radiation be considered?

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  - ☐ If this doesn't work, is immunotherapy still an option later, or is there a clinical trial to consider?

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## Clinical Trials for Advanced SCC

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

Appointment date

Doctor's name

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

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

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

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- ☐ If I am a transplant recipient or otherwise immunosuppressed, is this trial designed with that in mind?

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

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

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

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

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## SCC in Transplant and Immunosuppressed Patients

Advanced Squamous Cell Carcinoma

<https://www.beatingskincancer.com/squamous-cell-carcinoma/advanced-scc/scc-in-transplant-and-immunosuppressed-patients>

Appointment date

Doctor's name

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- ☐ How often should I have full-body skin exams given my transplant or immunosuppression?

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  - ☐ Is my current immunosuppression regimen something we should reconsider given my skin cancer history?

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  - ☐ If my SCC becomes advanced, is immunotherapy an option for me, or too risky because of my transplant?

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  - ☐ Who would be involved in that decision — my transplant team, oncologist, or both together?

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  - ☐ What non-immunotherapy treatments would we try first, and how effective are they typically?

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  - ☐ Is there a specialized center or clinical trial studying safer immunotherapy protocols for transplant recipients like me?

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## Questions to Ask Your Care Team About Advanced SCC

Advanced Squamous Cell Carcinoma

<https://www.beatingskincancer.com/squamous-cell-carcinoma/advanced-scc/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?  
\_\_\_\_\_
- ☐ Does my pathology report show any high-risk features, such as poor differentiation or deep invasion?  
\_\_\_\_\_
- ☐ Is there any sign the tumor is growing along a nerve (perineural invasion)?  
\_\_\_\_\_
- ☐ Do I need imaging (CT, MRI, or ultrasound) of the lymph nodes, and is a sentinel node biopsy being considered?  
\_\_\_\_\_
- ☐ Has my tissue been reviewed by a dermatopathologist here, or should the slides be re-reviewed?  
\_\_\_\_\_
- ☐ Am I on immunosuppressing medication or have I had an organ transplant — does that change the plan?  
\_\_\_\_\_
- ☐ 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?  
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- ☐ 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, cartilage, bone, the eye?  
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- ☐ 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?  

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- ☐ 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, including any lymph node surgery:*

- ☐ What exactly would be removed, and how would that affect how I look, speak, chew, or see?  

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- ☐ How likely is it that you will get clear margins in one operation? What if you do not?  

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- ☐ Will lymph nodes be removed or sampled, and how will that change my recovery?  

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- ☐ What is the recovery like — hospital stay, time off, drains, wound care?  

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- ☐ Is radiation or medication likely to be recommended after surgery?  

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- ☐ 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, is it being added after surgery, or is it aimed at the lymph nodes as well as the primary tumor?  

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- ☐ How many sessions, over how many weeks, and what does a session involve?  

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- ☐ What are the short-term effects (skin irritation, fatigue, difficulty swallowing) and the long-term ones for my treatment area?  

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- ☐ Do I need a dental evaluation or other preparation before starting, especially for head and neck radiation?  

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- ☐ What is the chance radiation controls the tumor long term, given its size, location, and nerve involvement?  

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- ☐ 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 immunotherapy, chemotherapy or an EGFR-targeted drug, 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?
  - ☐ If I have had a solid-organ transplant or take immune-suppressing medication, is immunotherapy still safe for me, and who is coordinating that decision with my transplant team?
  - ☐ 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?
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## 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?
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- ☐ What does follow-up look like once active treatment ends?
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## 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?
  - ☐ Do the lymph nodes need to be checked or treated?
  - ☐ What are my treatment options, and which do you recommend and why?
  - ☐ Has a multidisciplinary team reviewed my case?
  - ☐ Who is my main point of contact, and how do I reach them?
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## Living With Advanced SCC

Advanced Squamous Cell Carcinoma

<https://www.beatingskincancer.com/squamous-cell-carcinoma/advanced-scc/living-with-advanced-scc>

Appointment date

Doctor's name

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- ☐ Is my SCC locally advanced or has it spread to lymph nodes or elsewhere, and what does that mean for my outlook?

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

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

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

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

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

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  - ☐ What support is available for my caregiver?

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