

DCIS QUESTIONS

To Ask Your Doctor: Diagnosis, Risk & Long-Term Monitoring

A DCIS diagnosis can leave you with more questions than answers. You may be told you have “Stage 0 breast cancer” and immediately presented with treatment options.

You do not have to make a decision before you understand your diagnosis, your individual risk, and your options for monitoring.

How to use this list

Bring it to your appointment. Print it, save it to your phone, or share it with someone you trust. Check off what you have asked and write answers in the space provided.

Your rights as a patient

You are allowed to ask questions. You are allowed to take your time. You are allowed to seek a second opinion. Ask your doctor if you can audio record your appointment.

Date _____ Dr. Name _____

12 Questions to Ask Your Doctor

1 Do you believe DCIS is “cancer,” “pre-cancer,” or a risk for future invasive cancer?

Ask what DCIS means in *your particular case* and what your doctor believes it means for your future risk. DCIS is classified as **Stage 0 and noninvasive** because the abnormal cells are confined to the milk ducts. Understanding exactly what you have — and what you don't have — is the first step.

If a biopsy is recommended: ask about the clip / marker

- ☐ Is a clip/marker necessary? Can I avoid one if I plan not to pursue immediate surgery?
- ☐ What is its purpose in my particular situation?
- ☐ Are there potential complications or allergic reactions associated with it?
- ☐ **Are there studies on the long-term effects or safety of leaving a clip/marker in the body?**
- ☐ Are clips/markers the same at all imaging centers, or are there different types and materials? What type and material would you use?
- ☐ Could it affect future imaging, biopsies, MRI, or other procedures?

2 Can you explain my pathology report, including my grade of DCIS, ER/PR status, and any other points of concern?

- ☐ What **grade** is my DCIS — low, intermediate, or high?
- ☐ What is my **ER/PR status**, and what percentage is ER-positive and PR-positive?
- ☐ Is there **necrosis**? If so, how much?
- ☐ How extensive is the DCIS? Can you show me where on my breast?
- ☐ How was the size or extent determined? How much was biopsied, and where?
- ☐ How confident are you that the biopsy represents the entire area?
- ☐ Are there any signs of **microinvasion or invasive cancer**?
- ☐ Where can my pathology be reviewed by a **breast pathologist** for a second opinion?
- ☐ Can I have a copy of my complete pathology report?

3 Are there ways to determine my individual risk for future invasive cancer?

DCIS is not one-size-fits-all.

- ☐ What factors make my DCIS higher or lower risk? What is my estimated risk of developing invasive breast cancer?
- ☐ How do my age, the size of my DCIS, the grade, and necrosis each affect my risk?
- ☐ Does my hormone receptor status affect my risk? My family history? My genetic profile?
- ☐ **Can a genomic or biomarker test provide additional information about my individual risk?** What does that test tell me, and what can't it tell me?

Ask for absolute numbers

Instead of “this doubles your risk,” ask: “**What is my actual risk in numbers?**” and “**What is my risk if I choose monitoring compared with treatment?**” Understanding absolute risk makes it much easier to evaluate your options.

4 What is your opinion on the DCISionRT biomarker test? Can you order this test for me?

- ☐ Is DCISionRT appropriate for my situation? What information could it provide about my individual risk?
- ☐ How might the results affect my decisions? What are the limitations of the test?
- ☐ Are there other biomarker or genomic tests I should consider?

5 What is your opinion of the COMET study and active monitoring trials for low-risk DCIS?

- ☐ What do you think the COMET study tells us? Am I similar to the women included in the study?
 - ☐ Are there other active monitoring studies I should know about? Clinical trials I may qualify for?
 - ☐ What are researchers learning about which DCIS is more or less likely to progress?
 - ☐ Are there studies evaluating new approaches to monitoring DCIS?
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6 Are there resources you recommend for learning more about DCIS or for peer support?

- ☐ Evidence-based educational resources and DCIS-specific organizations
- ☐ Peer support groups and patient advocates
- ☐ Clinical trial resources and research studies I can read myself

You don't have to rely on one appointment or one source of information.

7 Are there diet and lifestyle recommendations to reduce my risk of future invasive cancer?

- ☐ Is there evidence that diet can affect future breast cancer risk? Are there specific dietary patterns you recommend?
- ☐ What physical activity do you recommend? Does maintaining a healthy weight matter?
- ☐ What role does alcohol play? Are there environmental or lifestyle factors worth considering?
- ☐ Are there evidence-based integrative or wellness resources you recommend?

Be clear about what is **supported by evidence** versus what is speculation.

8 If I were interested in monitoring my DCIS, would you be willing to oversee my care?

- ☐ What imaging would we use, and how frequently would I be monitored? What would we establish as my baseline?
- ☐ What changes would trigger additional imaging? What changes would trigger a biopsy?
- ☐ What findings would cause us to reconsider monitoring? Can we agree on those criteria **before** beginning surveillance?
- ☐ Who will oversee my monitoring long term? What happens if my imaging changes — would I have time to make a decision?

“If I choose active monitoring, will you support me and work with me to create a safe, evidence-based monitoring plan?”

Your healthcare team should be willing to have an honest conversation about your priorities and preferences.

9 I have concerns about too many mammograms and MRIs. What are my options for monitoring DCIS long-term?

- ☐ What are my options for long-term monitoring, and how often do I actually need imaging?
- ☐ What are the advantages and limitations of mammography, ultrasound, and MRI?
- ☐ **What are the potential downsides of repeated conventional imaging over many years?**
- ☐ **Do I have dense breasts?** How does my breast density affect my imaging?
- ☐ **Can I obtain copies of my actual images**, not just the radiology reports? Where can they be reviewed by a breast-imaging specialist?
- ☐ Should I establish a **baseline scan** now for future comparison?

Ask about emerging breast imaging technologies

“What are your recommendations on emerging breast imaging technologies that may be safer for long-term monitoring?” Technologies to ask about include **ABUS** (Automated Breast Ultrasound), **AWBUS** (Automated Whole Breast Ultrasound, which can also evaluate the axillary region), and **QT Imaging** (a 360° view of the breast). Ask about the advantages, limitations, evidence, and availability of each.

10 Do you have patients who have been monitoring DCIS and incorporating healthy diet and lifestyle changes?

- ☐ Have you overseen patients who chose active monitoring? What protocols have you used?
- ☐ What have you learned from those patients? How do you evaluate changes over time?
- ☐ Are there lifestyle or wellness resources you recommend?

11 Do you have knowledge of alternatives to hormone-blocking medication?

- ☐ What benefit would hormone-blocking medication provide **for someone with my individual risk profile**?
- ☐ What are the potential side effects and long-term risks? What happens if I choose not to take it?
- ☐ Are there alternatives? What evidence exists for lifestyle approaches?
- ☐ How would we monitor me if I decide against it? Please explain the **absolute benefit**, not just the relative risk reduction.

12 What studies do you recommend I review?

- ☐ Which studies should I read? What research do you consider most important?
- ☐ Are there studies about active monitoring? About DCIS progression? About emerging imaging technologies?
- ☐ Are there studies about lifestyle and breast cancer risk? New clinical trials I should know about?
- ☐ **How can I stay informed about new research?**

You deserve to understand the evidence behind the recommendations being made about your health.

If Something Changes

Understanding what “change” means during monitoring

Changes on imaging don't automatically mean that invasive cancer has developed.

- ☐ What changes are you looking for? What constitutes meaningful progression?
- ☐ How do you distinguish a significant change from normal variation?
- ☐ How can inflammation, hormonal changes, or other factors affect imaging?
- ☐ If something changes, will another imaging modality be used before a biopsy? **What would make you recommend a biopsy?**

Understanding the **decision points ahead of time** can make long-term monitoring less stressful and more predictable.

If a biopsy is recommended

- ☐ Why do I need this biopsy? **What specifically changed, and how can we monitor that change first?**
- ☐ What information will the biopsy give us? Are there alternatives that could provide useful information first?
- ☐ What type of biopsy are you recommending, and why this type? What are the potential risks and complications?
- ☐ Could the biopsy affect future imaging or breast tissue? What happens if I decide to wait?

You can ask questions before consenting to a procedure.

Ask about second opinions

- ☐ Would you recommend a second pathology opinion?
- ☐ Can I have my imaging reviewed somewhere else?
- ☐ Can I obtain copies of my pathology slides, reports, and imaging for another opinion?

A second opinion doesn't mean you don't trust your doctor. **It means you are gathering information — and DCIS pathology results can vary from doctor to doctor.**

Before You Leave Your Appointment

Make sure you know:

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| ☐ Exactly what your pathology says | ☐ Your imaging options |
| ☐ Your DCIS grade and extent | ☐ Your long-term monitoring options |
| ☐ Your ER/PR status and percentages | ☐ What would trigger additional testing or biopsy |
| ☐ Whether necrosis is present | ☐ Whether a second opinion would be helpful |
| ☐ Your breast density | ☐ Whether you qualify for a clinical trial |
| ☐ Your individual risk factors | ☐ When your next appointment or scan should be |
| ☐ Whether a biomarker test may be appropriate | ☐ Who will manage your long-term monitoring |

And get copies of your:

Pathology report • Imaging reports • Actual imaging • Other relevant medical records

Remember: you are part of the decision

A diagnosis does not mean you have to stop asking questions. Your healthcare decisions should be based on your individual situation, the best available evidence, and your own values and priorities. Research is changing. Imaging technology is changing.

Stay informed. Ask questions. Seek second opinions. Know your numbers.

Considering active monitoring? Ask: **“What would a safe, evidence-based monitoring plan look like for me?”**

Notes From My Appointment

Information is power. Informed consent is nonnegotiable.

More resources at
dcis411.com

DCIS 411 is a public service website, independently created and maintained. Information here is for educational purposes only and is not medical advice. See the full disclaimer at dcis411.com/disclaimer.