

Preparing for Your Appointment and Questions for Your Doctor

Consulting with a doctor (or doctors) to discuss your DCIS diagnosis and treatment can feel overwhelming. Below are some tips to help you prepare for and navigate your appointment:

- Gather and review your radiology and pathology reports, as well as any other relevant test results or doctor's notes. Retaining a copy of your imaging (typically available on CD), will be helpful if you go on to get additional opinions.
- Prepare a written list of any questions you have about your reports, as well as about your specific diagnosis, your individual risk profile, additional diagnostic testing and treatment options (see below).
- Take notes or record the conversation (with the doctor's permission) to help you keep track of all the information. If you have a family member or friend who can accompany you on the visit or participate via phone, you can ask them to take notes. Having a supportive person with you at the visit can also help ensure that all your questions are sufficiently addressed.

Below is a list of some of the questions that you might want addressed:

Questions About Initial Exam, Imaging and Pathology Report

1. How large is my DCIS? What does this mean and how does this impact my treatment?
2. Where in my breast is the DCIS located? Can you feel it? Can you show me where it is?
3. Do I have more than one area of DCIS? If so, are the other areas in the same quadrant of the breast? Are there any in the other breast?
4. What grade is my DCIS? What does this mean and how does this impact my risk level?
5. How does my DCIS appear to be growing (cribriform, papillary, micropapillary, comedo or solid) and does this impact my risk level or treatment?
6. Are there signs of comedo necrosis? If so, does this impact my risk level or treatment?
7. Is my DCIS estrogen-receptor positive (ER+) and/or progesterone-receptor positive (PR+)? If it is ER+ or PR+, how strong is the positivity? What is the significance of these results for me and my treatment?
8. How confident are you in the results from the radiology and pathology reports? Is there any reason to get a second opinion on those tests?

Questions About Additional Testing and Assessing Risk

1. Would you categorize my DCIS as low or high risk? What factors are you basing that decision on?
2. Do you recommend any additional diagnostic screening tests such as an ultrasound or MRI? Why/why not? What additional information can these tests provide? Are there any downsides to these additional tests?
3. Do you recommend genetic testing? Why/why not? If yes, what will you test for? When will this happen? How will the results impact my risk level and your treatment recommendations?

4. Do you plan on sending a specimen for Oncotype DX DCIS or DCISionRT for testing? Why/why not? Can you send a specimen from my recent biopsy, or will it be a specimen from future surgery? How will the results impact my risk level and your treatment recommendations?
5. How does my age, family history, lifestyle and/or other health conditions impact my risk level and your treatment recommendations?

Questions About Treatment – General

1. I understand that many DCIS patients may have more than one treatment option. Do you think there is more than one version of a potential treatment plan for me? If so, can you lay out the pros and cons of each?
2. Are you recommending surgery, radiation and/or hormone therapy? Please explain the reasons for this treatment plan.
3. What is the order and time frame for each of these treatments? If I experience side effects, who should I reach out to?
4. In making your treatment recommendations, do you take into consideration my personal preferences that stem from considerations such as my lifestyle, age, familial/work obligations, financial concerns and/or preferred cosmetic results?
5. Am I a candidate for active surveillance? Are you familiar with the COMET trial? Would you be willing to follow me on active surveillance if I meet the qualifications for the COMET trial?
6. Am I a candidate for any other clinical trials? What are the benefits and drawbacks of enrolling in a clinical trial?
7. Are you open to me sharing with you any new studies/research/clinical trials I may come across?
8. If I undergo (surgery/radiation/hormone therapy/surveillance) treatment, what is my risk of invasive breast cancer or DCIS recurrence in the next 10 years? 20 years?
9. If I undergo (surgery/radiation/hormone therapy/surveillance) treatment, what is my risk of dying of breast cancer in the next 10 years? 20 years?
10. Do you recommend any dietary or lifestyle changes?
11. Are you comfortable with me seeking additional opinions if I choose to do so?

Questions About Surgery

1. Do you recommend a lumpectomy or a mastectomy for me? What are the risks and benefits of each? What are the short and long-term side effects of each?
2. If you are recommending a lumpectomy, do you think you can achieve clear margins in my case? If you cannot obtain clear margins the first time, will you recommend a second lumpectomy? Under what circumstances would you recommend that I have a mastectomy after a lumpectomy?
3. If I have a lumpectomy, do you recommend radiation? If so, can you explain why? How much will radiation decrease my chances of future invasive breast cancer, DCIS recurrence, and/or of dying from breast cancer?
4. If I have a mastectomy, can I avoid radiation and/or hormone therapy?
5. What technique do you use to locate the area of DCIS before surgery?
6. How long will the surgery take and will it be inpatient or outpatient?
7. What can I expect in terms of anesthesia?

8. How will you determine whether the margins are clear? What techniques do you use? Will it be possible to test for clear margins in the operating room, and if they have not been obtained, for you to do an additional excision immediately?
9. Are you familiar with oncoplastic lumpectomy (removing tissue to obtain clear margins while at the same time rearranging the tissue in one or both breasts for a better cosmetic result), and am I a candidate? Will I need a plastic surgeon for this technique?
10. Are you familiar with cryoablation (tumor freezing) as an alternative to surgery, and am I a candidate?
11. If I have a mastectomy, will you do a sentinel node biopsy to identify lymph node involvement? What does this entail and what are the side effects?
12. If you are recommending a mastectomy over a lumpectomy, can you explain why? Will it affect my future risk of invasive cancer, DCIS recurrence and/or of dying from breast cancer? What are the downsides of a mastectomy as compared to a lumpectomy?
13. If I have only been diagnosed with DCIS in one breast, do you recommend a bilateral mastectomy (removing the opposite breast)? Why or why not? Can I elect a bilateral mastectomy even if you do not recommend it?
14. What is my risk of developing DCIS or invasive cancer in my opposite breast if it is not removed?
15. Can you do a skin-sparing and/or a nipple-sparing mastectomy? Will I have any sensation in my breasts or nipples after the surgery?
16. What are my options if I choose to have breast reconstruction? Do you coordinate with a plastic surgeon? Do you recommend flap reconstruction or implants? Or aesthetic flat closure? Can you explain the pros and cons of each? How will my nipple and areola be reconstructed?
17. What is the difference in recovery time for mastectomy with and without reconstruction? How many surgeries will I need if I choose implants? If I choose flap? What is the timing of these surgeries?
18. Can you show me photos of what my chest may look like after reconstruction?

Questions About Radiation

1. If I undergo radiation, how much will it reduce my risk of future invasive cancer, DCIS recurrence, and of dying from breast cancer?
2. What are the short and long-term side effects of radiation? Is there anything I can do to minimize these side effects?
3. What type of radiation is recommended? Will it be whole breast or partial? Can you explain the differences and why you recommend the one you do?
4. How many radiation treatments will I have?
5. Can I choose the location for my radiation treatments and if so, if there one you recommend?
6. What are the risks of radiation including the risks of developing other cancers? Are there techniques to protect my heart and other organs that might be near the radiated area?
7. Will having radiation affect my future surgical options should I have a recurrence?

Questions About Hormone Therapy

1. If I undergo hormone therapy, how much will it reduce my risk of future invasive cancer, DCIS recurrence, and of dying from breast cancer?
2. Which hormone therapy are you recommending and why?

3. When will I start the hormone therapy and how long are you recommending that I take the medication? What will happen at the end of that time period? What happens if I stop taking the medication before the fully recommended time frame?
4. Does the medication interact with any of my current medications and will I need to stop taking any of them?
5. What are the greatest risks associated with the medication? Are there any potential negative effects on my bones, heart, vision or weight? Does taking this medication increase my risk of developing other cancers?
6. What are the most common side effects? What are some of the less common side effects? Who should I talk to about the side effects? Should I expect the intensity of side effects to change over time? Is there an option for switching medications or lowering the dose if the side effects are too great? Is there an option to take periodic breaks from the medication during the treatment period?

Questions About Follow-up

1. How long will my recovery be from a mastectomy? From a lumpectomy? Who will follow-up with me after surgery and when/how many follow-up visits will I have?
2. If I have a mastectomy, will I have to have drains put in? For how long?
3. Will you prescribe pain medications? Who should I contact if I continue to have pain after surgery?
4. Am I at risk of getting lymphedema or cording after surgery? How will I recognize if I have lymphedema or cording? Are there any precautions I can take?
5. What can I do to ensure that I get back full motion of my arm(s) after surgery? Do you recommend breast physical therapy or lymphedema massage? Can you refer me for this care?
6. How will I be followed after treatment? Will I need to get check-ups, scans and/or blood tests? How often?
7. What type of imaging will you recommend and how often? Do you recommend that I be followed with MRIs or ultrasounds in addition to mammograms?
8. Should I continue doing breast/chest self-exams and checking under my arms for swollen nodes?
9. Do I have dense breasts? Will you consider this when you order future scans? Are there any guidelines for imaging tests or timelines for follow-up if I have dense breasts.

Notes: