

Finding the Right Care for Your Needs

Finding the Right Doctor for You, Second Opinions, Specialists, Overcoming Barriers

Please note: The information presented here is intended for educational purposes and is for general orientation. It is not intended, nor should it be interpreted, as medical advice or medical instructions or to replace your doctor's advice. You are advised to consult your own medical doctor(s) for all matters involving your health and medical care.

Finding the Right Doctor for You

Treating thyroid cancer often involves a team of physicians, with one physician as the team leader. You will likely see several doctors in addition to your family doctor, especially in the first few years of treatment and follow-up.

Your care team is likely to include your primary care physician, an endocrinologist, a surgeon, and a nuclear medicine specialist. A pathologist will also be involved with your care team.

Some patients with aggressive or metastatic disease may also consult with or visit an oncologist. An oncologist is a doctor who specializes in cancer treatment, and some oncologists have specific areas of specialty, such as endocrinology.

Some endocrinologists and surgeons have chosen to specialize in treating patients with thyroid cancer. This decision should result in them having more experience treating patients dealing with similar circumstances and should result in fewer complications for patients. Additionally, these physicians should be knowledgeable regarding the medical association practice guidelines.

Points to Consider

- If you have one of the more frequently diagnosed types of papillary or follicular thyroid cancer diagnosed at an early stage, many physicians have extensive knowledge and experience. In this case, it may not be necessary to consult with an expert.
- If you have a less common type or situation with your thyroid cancer (such as medullary, anaplastic, pediatric, or advanced papillary or follicular disease defined as disease that doesn't absorb radioactive iodine), it will be important to seek out more specialized expertise for that particular type of thyroid cancer.

What are Clinical Practice Guidelines?

Clinical practice guidelines are papers published by major medical associations (such as the American Thyroid Association) to help clinicians give their patients the best possible care. They represent general guidance and principles, rather than rigid instructions.

While these guidelines are written for medical professionals and most patients are not aware of them, most guidelines for care are available for free online for anyone who wants to read them.

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- If the patient is a child or teen, a specialist experienced with thyroid cancer in children and teens is often helpful.
 - If surgery will be part of the treatment, it is important to find an experienced thyroid surgeon who does large numbers of thyroid surgeries every year. Studies show that surgeons that perform more than 25 thyroid surgeries a year have lower complication rates. The lowest complication rates occur when a surgeon does at least 100 surgeries a year. Thyroid surgery complications may include voice issues or parathyroid (calcium) issues.
 - You and your caregivers need physicians who are willing to consult with specialists if needed. Do not hesitate to get a second opinion, or seek out a specialist. If you think you should get a second opinion, you should get it. Your doctor should support and encourage this decision. You are also a member of your care team and you should feel informed about and involved with your care.
 - A doctor treating thyroid cancer must also be open to reviewing the latest clinical practice guidelines and research literature, as well as discussing treatment options with researchers and experienced clinicians, including those involved in clinical trials of new treatment (if needed).
 - For some patients, it can be helpful to consult with or receive care from a specialist in the early years of treatment and follow-up. After that, if your situation is low-risk and stable, your primary care professional or a local non-specialist may be appropriate for handling your long-term monitoring, including thyroid hormone replacement and any ongoing thyroid area and neck imaging.
 - ThyCa's website (www.thyca.org) has links to professional associations with lists of their member physicians involved in thyroid cancer care. The website also connects visitors with sets of physician guidelines for the care of different types of thyroid cancer. The website also links to numerous online and face-to-face thyroid cancer support groups connected to ThyCa. Participants in online and face-to-face support groups also often share names of specialists involved in their own care.

Should I Get a Second Opinion?

It is your right as a patient to get a second opinion if you want one. Second opinion appointments are a way to get peace of mind. If your doctor doesn't support you getting a second opinion, you should ask why.

Remember that getting a second opinion typically requires getting a copy of your medical record, lab work, pathology reports and imaging. This is one reason it is important to talk to your doctor about a second opinion. Your doctors' offices should be able to help you collect this information. You should consider collecting copies of your medical records for your own files anyway.

If you're thinking about getting a second opinion, go ahead. It is understandable to feel unsure about what is happening. This is very common. Getting a second opinion can help you understand your options. In most cases a second opinion will confirm your current treatment course.

You can and should think about and explore your options. You should absolutely feel comfortable in saying to your doctor, "I am not sure what I need to do, but I think I need a second opinion."

In particular, consider a second opinion if your treatment may involve significant side effects or is invasive or lifelong.

Consider a second opinion if you aren't sure of the treatment plan your doctor is proposing.

Should I Look for a Specialist?

Thyroid cancer care requires a team of physicians, but not every patient needs to find a specialist. In fact, most thyroid cancer patients will not need to see a specialist.

Only about 5% of patients with thyroid cancer need to consult with a medical oncologist or an endocrine oncologist.

Being informed about the care of patients with different types of thyroid cancer can help you decide if you want to look for a specialist to help with your thyroid cancer treatment.

The main types of thyroid cancer are papillary, follicular, medullary, and anaplastic. There are also variants of these main types of thyroid cancer. Your doctor should communicate with you clearly about which type of thyroid cancer you have, and if you are not sure, it is important to ask for more information.

The type of thyroid cancer you have will determine the type of treatment you need. Patients' medical situations vary widely. Most commonly, patients are diagnosed with low-risk papillary or follicular thyroid cancer that has very high long-term survival rates.

However, some patients are diagnosed with high-risk thyroid cancer that is metastatic, progressing, and life-threatening. These diagnoses are more serious. They require more immediate, long-term, and more specialized care. Patients with high-risk thyroid cancer should strongly consider finding a specialist with expertise in treating their specific type of thyroid cancer, to ensure the best care possible.

When Should I Talk with a Specialist?

Not every patient needs a specialist, but those with high-risk thyroid cancer should find a specialist endocrinologist, surgeon, and oncologist who are experienced in high-risk thyroid cancer.

In looking for a thyroid surgeon, it is best to find one who performs more than 25 thyroidectomies a year. Statistics show an experienced thyroid surgeon will have a lower complication rate. Surgeons that perform more than 100 surgeries a year typically have the lowest complication rates.

In looking for an oncologist, it is best to find one with a particular interest in endocrine oncology. Look for a subspecialty of a medical oncologist who specializes in endocrinology or an endocrinologist with a special interest in thyroid cancer specifically.

Patients should talk with a specialist if they have:

- Anaplastic thyroid cancer
- Medullary thyroid cancer
- Any type of advanced metastatic papillary or follicular cancer, if it does not respond to radioactive iodine, and if the cancer has spread beyond lymph nodes in the neck to other parts of the body

Specialized expertise is important for these patients, to be sure that they receive the best care possible.

How to Find a Specialist for Your Situation

There are several ways that you can find a specialist and several ways to access care from them.

If you are being treated by a community physician, you can ask your doctor if you should see a specialist. In the medical field, “center of excellence” refers to medical facilities with very high quality care for a particular disease, as well as good patient outcomes.

You may want to ask your doctor if you should seek care at a center of excellence, particularly if you have medullary or anaplastic thyroid cancer, or metastatic papillary or follicular thyroid cancer that is refractory to radioactive iodine (doesn't absorb radioactive iodine). ThyCa's web site (www.thyca.org) has links to professional associations with lists of their member physicians involved in thyroid cancer care.

A center of excellence will also be an academic or teaching hospital, typically connected to a university.

Finding an online or face-to-face support group can offer comfort and support. Other participants are often willing to share the names of specialists involved in their own care.

If you feel comfortable doing so, talk about your diagnosis with others. You never know when someone may know someone who is coping with your cancer, or may know a doctor you should talk to, or know of a treatment option. Or, you may meet someone who just wants to help you and offer emotional or practical support when you need some help.

Keep in mind that other patients results do not guarantee that you will have the same outcome. Additionally, some patients will choose a doctor because they like the person. You want to select a physician you believe can provide you the best, most sound medical care.

If your physician is not personally experienced with your type and situation with your thyroid cancer, ask whether they can refer you to a specialist. Most physicians are experienced with patient requests for getting a second opinion and should be supportive of you exploring your options.

Once referred to a specialist, ask that specialist what experience they have in treating your type of thyroid cancer, and how often they see patients in your situation. You can also ask whether the doctor is open to discussing treatment options with researchers and experienced clinicians, either locally or at a distance.

Overcoming Barriers to Receiving Expert Consult

Access to a specialist can take one or more forms:

- Patient's physician consultation with an expert
- Patient telephone consultation with an expert
- Direct patient care, in person

Many patients feel disheartened if there is no specialist within their area. Some patients can travel long distances for care, but for others, a telephone consultation with an expert can be a way to access care with a specialist.

Even though you may live more than 50 miles from an expert, you still can speak with one. Additionally, your doctor may feel better prepared and more confident in treating your thyroid cancer after consulting with a medical expert.

In addition to travel distance, there are many other barriers that can limit your access to specialist care including but not limited to:

- Ability to pay for travel
- Ability to pay for medical care

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- Health insurance issues including not having health insurance
 - Work situation
 - Family situation

If you experience barriers to finding a specialist, discuss these with your doctor to see if there may be a solution you can both agree on.

Next Steps After Finding a Specialist

Once you have found a specialist and made an appointment, there are some ways in which you can prepare for the appointment.

Prior to the appointment, ask for the physician's or medical center's guidelines on how to prepare for your appointment. Ask what records, lab reports, pathology reports, and imaging reports they need from you. The following list includes some things you can bring to the meeting:

- Bring a picture ID, your health insurance card if you have one, and your referral, if required by your insurance.
- Bring a summary of your health history, including reports from all thyroid cancer doctors.
 - Examples: pathology report from FNA, scan/imaging results, surgical report, with related pathology report.
- Bring a list of medications you are taking.
 - This includes prescription medications, over-the-counter medications, and nutritional supplements, including dose (strength) and frequency (number of times you take it each day).
- Bring a written list of questions for your specialist
 - Cancer treatment may be a very stressful process. It is helpful to write down your questions so that you don't forget to ask about anything that is important to you.
- Bring notebook and a pen and paper, to take notes.
 - You may find it helpful to make notes of the doctors' answers/instructions, to be sure you don't forget what was discussed. You can keep your notes and records in a loose-leaf 3-ring binder, or in file folders, to help organize them. Consider keeping a special tote bag to carry your notebook, notes, lab orders, and other papers to your appointments.
- If possible, bring someone with you to also take notes. A second set of ears can be invaluable at any medical appointment.

- Bring something to keep you busy and calm while you wait.
 - It is a good idea to arrive 15 minutes or more before your appointment. There may be forms for you to fill out. You may have to wait for your appointment because doctors cannot predict how much time they need to spend with each patient.

Tips for Communicating with Your Doctor

Good communication with your doctors is one of the keys to getting good medical care. You want the best care. You are coming to the doctor for medical care, and since you are part of your care team, you want to feel heard and empowered to ask questions. Of course, many people get nervous when seeking medical care, and appointments may seem to go quickly. Here are some helpful hints that may prepare you for in-person interactions with your doctor or someone from your care team:

- Take a family member or friend to the appointment. Two sets of ears are better than one.
- Cancer treatment may be a very stressful process. It is helpful to write down your questions so that you don't forget to ask about anything that is important to you. You may also find it helpful to make notes of the doctors' answers/instructions.
- Take lots of notes. Details of the proposed care or of your diagnosis may be difficult to remember, and doctors use a lot of medical jargon. Ask your doctor to spell things out for you, if you are writing them down. Feel free to ask for an explanation of unfamiliar terms and definitions. Feel free to ask, "I want to make sure I understood you correctly. Did you say ...?"
- Ask for a visual aid. Seeing what your doctor is talking about on a chart or visual aid can help you remember. Doctors often have fact sheets or pamphlets they can give out, so be sure to ask if they have any printed information to give you. Your doctor may also recommend you go to the ThyCa website for materials and support.
- Ask questions. Be your own advocate. Let your doctor know what is most helpful for you to understand what is going on in your body and what the treatment should be.
- Always ask for copies of your medical records. This allows you to review the information more than once. Reviewing medical records helps some people feel more in control of their medical situation.
- Talk about your diagnosis with others. You never know when someone may know someone dealing with your cancer, or may know a doctor you should talk to, or know of a treatment option. Or, you may meet someone who just wants to help you when you need some help. ThyCa Support Group Meetings are a safe place to talk with others about your journey.