

Communication is key

It is important to keep detailed notes about your condition, your symptoms, and your overall health. Sharing this information with your healthcare team may better prepare them to help you.

You may have questions that you want to ask the members of your healthcare team. Perhaps you want to know about a new symptom you are experiencing. Or you may need to have test results explained to you more clearly. It is important to ask these questions and carefully record the answers.

Here are some sample questions that can help you begin the discussion with your doctor. You can ask them as they are written here, or they may prompt further questions about your specific situation.

Questions to ask my oncologist

About my condition

- Where can I find more information about neuroendocrine tumors (NETs)?
- How big is my *tumor*?
- Are you able to find my primary tumor? Where is it located?
- Has my disease spread to other parts of my body?
- What do the terms “*grade*” and “*stage*” mean? What are the grade and stage of my disease?
- How much experience do you have with NETs?
- Should I get a second opinion?

About my care

- What tests or procedures are necessary? How often will I need them? How will they be used in developing my care plan?
- Are there things I need to do, or not do, before each test or procedure?
- What is the goal of my care plan? What is the timeline for my care plan?
- What can I do to get ready for my care?
- How will my care plan affect my daily life? Will I be able to work and perform my usual activities?
- How can I keep myself as healthy as possible?
- Could my care plan affect my ability to have children?

About ongoing follow-up

- How often will I need to see a doctor?
- What tests will I need? How often will I need these tests?
- How can I get copies of my laboratory test results?
- What support services are available to me and my family?
- Whom do I contact about problems or questions I may have about my care plan?
- Where can I find help with handling the cost of my cancer care?

Italicized terms are defined in the glossary on the last page of this fact sheet.

Talking with my healthcare team



Questions to ask my surgeon

Before surgery

- How much of your surgery is focused on cancer? Do you have experience with NETs?
- Do I need tests before this surgery? Can you explain them to me?
- Do I need a biopsy? Can you explain what this is? What is a biopsy used for?
- Will there be a pathology report? Can I get a copy? Who will explain it to me?
- How soon do I have to make a decision about surgery?
- What should I do to get ready for the surgery? Are there any foods or medicines I should stop taking?
- How long will my surgery take?
- Can you describe what you will do during the surgery?
- What are the risks and side effects of this surgery? How will I know if there is a problem? Should I call you?
- Will I need to stay in the hospital for this surgery? If so, how long?
- Will I have stitches, staples, or bandages?
- Will there be a scar? Where will it be located?
- Are there any permanent effects from this surgery?
- What does it mean to have a surgical drain? Will I need one?
- When will I need to return for a follow-up appointment?

After surgery

- Will I have side effects after surgery? What can be done to ease them?
- How long will it take me to recover after the surgery?
- Are there instructions or materials about postoperative care that I can take home with me?
- Do I need additional surgery?

Talking with my healthcare team

Questions to ask about my health insurance

It's not always clear who the best person is to answer questions about your health insurance.

Your doctor or other members of your healthcare team may be able to answer some of your questions. Doctor's office support staff, nurses, case managers, and patient advocacy groups may also be able to help. And, of course, representatives from your insurance company can help answer questions about your specific health plan.

The following questions can help begin the discussion about your health insurance coverage.

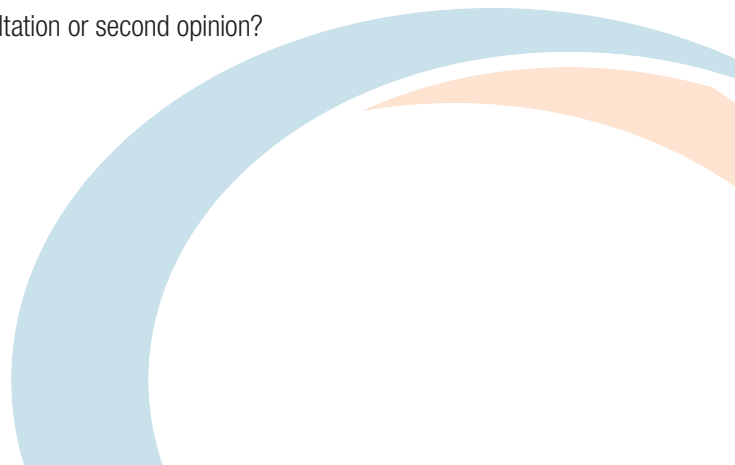
About my doctor visits

- Who at this office will answer my questions about health insurance?
- Will this person help me work with my insurance company?
- Can this person help me understand my medical bills and the billing codes to make sure they are correct?
- How much is my co-pay for each doctor visit? When is this payment due?
- Do you offer any payment plans?
- Will I be billed separately for laboratory tests? Are these tests covered under my health insurance?
- If an insurance claim is denied, who can help me file an appeal?

About my hospital visits

- Is the hospital or facility being recommended to me in my insurance plan's network?
- If I need to be admitted into the hospital, what will be covered under my medical insurance?
- Will there be a co-pay for each individual visit? When are these payments due?
- Do you offer any payment plans?
- If an insurance claim is denied, who can help me file an appeal?

About my insurance coverage

- How can a nurse case manager help me? How can I have one assigned to me?
 - Is there a limit to how much my insurance will cover for my care? If so, are my medical bills likely to reach that amount?
 - Who can help me understand how to read my medical bills and explanations of benefits?
 - Are outpatient visits covered under my medical insurance?
 - Does my insurance company need to approve any or all of my management plan before I begin?
 - Does my insurance cover other doctor visits, such as for a consultation or second opinion?
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Talking with my healthcare team

Important terms

Grade: A system of classifying tumor cells. The cells are graded based on how abnormal they look under a microscope and how quickly the tumor is likely to grow and spread. Low-grade tumors (grades 1 and 2) closely resemble surrounding tissue and are less aggressive. High-grade tumors (grades 3 and 4) do not resemble surrounding tissue and are more aggressive.

Stage: The extent of a cancer in a person's body. Staging is usually based on the size of the tumor, whether lymph nodes contain cancer, and whether the cancer has spread from the original site to other parts of the body.

Tumor: An abnormal growth or mass in the body caused when cells grow uncontrollably or fail to die when they are supposed to.