

Questions to ask

It can be difficult to know what questions to ask at an appointment with a medical specialist.

Asking questions will help you understand more about your type of neuroendocrine cancer and how and why decisions about treatment are made.

It is ok if you don't know where to start. This fact sheet can help guide you.

General Neuroendocrine Cancer questions

- What type of NET do I have?
- Where in the body is the NET located? Has it spread to other parts of the body? If it has spread, where has it spread to?
- What are the risk factors for NETs?
- Are you a NET Specialist? How many NET patients do you treat a year?
- Are you able to discuss my case with or refer me to a NET Specialist?
- Are you involved with or have access to a NET Multidisciplinary team?

Diagnosis, tests, and investigations

- What can the biopsy/surgery histopathology report (the description of neuroendocrine cancer as it looks under a microscope) tell us?
- Did an experienced pathologist who understands NETs review the tumour?
- What tests do I need to have? Refer to the optimal care pathway for people with NETs for specific investigations related to the NET location.

<https://www.cancer.org.au/assets/pdf/neuroendocrine-tumours-1st-edition>

Grading and staging

- What is the grade of my NET (the description of the NET when looked at under a microscope)? What does this mean?
- What is the stage of my NET? What does this mean?

- Based on my grade and stage, what is my likely prognosis?
- What is Ki 67 % and what does it mean?

Treatment and management of NETs

- What are my treatment options?
- What is the treatment called and how does it work?
- Why is this treatment recommended?
- What is the goal of treatment? Is it to remove the cancer completely, to control the cancer, to manage the cancer symptoms?
- How soon do I need to commence treatment; urgently, semi urgently, non-urgent?
- How often do I need this treatment? (Treatment schedule)
- Will the treatment reduce my NET symptoms?
- Can I have written information about my treatment?
- Is there a home support program for this treatment, so I can have this at (or closer to) home?
- Where will I have my treatment? How long will it take (short appointment, day stay, overnight)?
- What are the side effects or risks (short term and long term) of this treatment?
- How can I best prepare myself for this treatment?
- What should I avoid or not do while having this treatment?
- How will this treatment affect my daily life? Will I be able to work, exercise and do my usual activities?
- Can I have a holiday while on treatment? Can I travel internationally while on treatment?



Support



Education



Research



Awareness



Advocacy

Questions to ask

Survivorship

- What is my follow up plan?
- Who should I contact if I experience symptoms again?
- Who will be the medical professional that will manage my follow up?
- What is the likelihood of my NET coming back/reoccurring?

Recurrence

- How do NETs spread when the margins were initially clear on the report from my surgery?
- What is the plan now?
- What scans, blood tests, investigations do we need to do?
- What are my treatment options?

Genetics

- Is my NET likely to be caused by genetic factors?
- Are any other members of my family at risk of developing a NET?

Clinical trials

- What are clinical trials?
- Are clinical trials relevant for my type of NET?
- What are the benefits and risks of participating in a clinical trial?
- How will I be monitored while participating in a clinical trial?
- What are my responsibilities in a clinical trial?
- Are there any costs associated with being in the clinical trial?
- Where can I learn more about clinical trials for NETs?

Finance

- What are the costs for my NET treatments?
- Are my treatments covered by Medicare, Pharmaceutical Benefits Scheme (PBS)?
- I am concerned about managing the costs of my care: who can help me?
- Am I eligible for benefits if I cannot work?

Support

- What support is available to me? To my family?
- Who should I call with questions or concerns out of hours?
- Where can I find out more about my NET?
- Do you know of any support groups or resources for NET patients?

For further free and confidential information and support contact our NET nurse telehealth service Monday-Friday 9-5pm

NET Nurse 1300 287 363.



Support



Education



Research



Awareness



Advocacy