

# Questions to ask during your consultation

## General:

- What type of NET do I have?
- Where is the NET located? Has it spread to other parts of my body?
- What are the risk factors for NETs?
- Is my NET likely to be caused by genetic factors? Are any other members of my family at risk of developing a NET?
- Are you a NET specialist? How many NET patients do you treat a year?
- Are you able to consult with or refer me to a NET specialist?
- Are you involved with or have access to a NET multidisciplinary team?
- Where can I find out more information about my NET?
- How could it have spread when the margins were clear from surgery?

## Tests

- What type of histology is my NET (the description of the NET as it looks under the microscope)? Did an experienced NET Pathologist review the tumour?
- What other tests do I need to have? (Refer to the diagnosis section. Tests may include blood tests such as chromogranin A (CgA); 24-hour urine tests (5-HIAA); functional nuclear medicine scans (Gallium-68 PET scan, FDG scan, ); triple phase CT of the liver; MRI; and echocardiography of the heart.

## Staging

- What is the grade and staging of my NET? What does this mean?
- Based on my grade and staging, what is my prognosis?

## Management

- What are my management options?
- What is the expected timeline for my management plan? Do I need to be treated immediately?
- Which treatments, or combination of treatments, do you recommend? Why?
- What is the goal of the treatment you are recommending?
- Can I have long overseas holidays whilst on treatment?

## Treatments

- What will be done during the treatment and how will it affect me?
- How often do I need this treatment? (Treatment schedule)
- Is there a home support program for this treatment, so I can have this at (or closer to ) home?
- Will I need to be hospitalised for a treatment, or is this treatment done as an outpatient?
- 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?
- Does this treatment treat my symptoms of NET?
- What are the costs for my NET treatments? Are my treatments covered by Medicare, Pharmaceutical Benefits scheme (PBS) or my insurance?

## Clinical trials

- What are clinical trials?
- Are there any relevant clinical trials for my 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 during a clinical trial?
- Are there any costs associated with being in the clinical trial?
- Where can I learn more about clinical trials for NET?

## Support

- What supports are available to me? To my family?
- Who should I call with questions or concerns out of hours?
- May I contact you or the nurse to talk about additional information I find?
- Do you know of any support groups or resources for NET patients?
- I am concerned about managing the costs related to my NET care: who can help me with these concerns?
- Am I eligible for any benefits if I cannot work?