

Neuroendocrine Tumour Service

This leaflet provides information about what to expect when you have been referred to the Neuroendocrine Tumour (NET) Service at King's College Hospital from another hospital. If you have any questions or concerns, please do not hesitate to speak to the team caring for you.

Why have I been referred to NET service at King's College Hospital?

Your local healthcare team have referred you to King's as they suspect or have confirmed that you have a neuroendocrine tumour. This is a relatively rare type of tumour. King's College Hospital is part of the King's Health Partners ENETS (European Neuroendocrine Tumour Society) Centre of Excellence, providing care and treatment for patients with neuroendocrine tumours. People with rare conditions benefit from having their cases reviewed by a team of specialists who are familiar with their condition and its treatment.

What happens next?

When we have received your referral, any scans you have had will be electronically transferred onto our electronic patient record system.

If you have had any biopsies or surgery, we will request the histology slides. These will need to be physically transferred to us so that they can be reviewed by our specialist histopathologists. This takes longer than transferring your scans and is usually the reason for any delays in discussing your case.

When we have received all the information we need, we will schedule a multidisciplinary team (MDT) meeting.

NET MDT meeting

The NET MDT meeting is held once a week on Thursday afternoon. The MDT is a team of doctors, nurses and other health professionals specialising in treating your type of cancer, including:

- NET consultant – a consultant with expertise in managing patients with neuroendocrine tumours. The consultant is also an expert in another field of medicine such as gastroenterology or hepatology (liver conditions)
- NET clinical nurse specialist (CNS) – an experienced nurse with expertise in caring for patients with neuroendocrine tumours
- radiologist – a doctor who specialises in reading and reporting scans such as MRIs and CTs
- nuclear medicine consultant – a doctor who specialises in reading and reporting scans such as PET scans as well as delivering nuclear medicine treatments
- histopathologist – a doctor who specialises in analysing tissue samples obtained through biopsies or operations
- oncologist – a doctor who specialises in the treatment of cancer

- surgeon
- NET MDT meeting coordinator – the administrator who gathers all the information and scans needed to discuss your case and sends the results of our discussions to your referring medical and nursing team

The MDT specialists will recommend what should happen next. Recommendations can include the need for further tests or scans, potential treatment options or an active surveillance plan. If the tumour is very small and has already been completely removed by a biopsy or removal of appendix, they may decide no further treatment or surveillance is needed.

What happens after the MDT meeting?

The NET consultants will authorise the recommendations and send them to your local healthcare team. Your local team or King's NET team will notify you of the recommendations.

If you need further tests or scans, they will be performed locally if possible. If any tests need to be performed at King's College Hospital, our NET CNS team or your local team will explain why.

You will be invited to an outpatient appointment with the NET consultant. They take place on Thursday morning or Monday afternoon. We appreciate that King's College Hospital may be a long distance from your home. Most first appointments are face-to-face, but we may be able to hold a telephone consultation in some instances.

Our outpatient clinic is held in the liver outpatient department, but that does not mean your tumour has spread or that there is anything wrong with your liver.

If the MDT recommends surgery, you may be invited to an appointment in the surgical clinic or for a joint appointment with a NET consultant and surgeon on the same day as your outpatient appointment.

There is usually a NET CNS in clinic. They will try to meet all patients on their first visit.

You can bring someone to your appointment, such as a family member or friend.

For further information about the support offered by the King's cancer service, please visit www.kch.nhs.uk/cancer

Contacting the NET CNS team

You can call or email the NET CNS team. Our calls are answered by Macmillan Support Workers. They can answer non-clinical questions and will message us about all clinical questions. We aim to return all calls or emails on the same day although this is not always possible, especially on Thursdays. There is no NET CNS service at the weekends or on bank holidays.

Tel: 020 3299 3854

Email: kch-tr.NETCNS1@nhs.net

Further information about neuroendocrine tumours

We use information produced by the charity Neuroendocrine Cancer UK. They are a charity that provides information on the various forms of neuroendocrine cancer and offers practical support for patients and families.

Website: www.neuroendocrinecancer.org.uk/