

King's Neuroendocrine Tumour Unit

An ENETS Centre of Excellence



Information for patients

Your doctor has referred you to us to help investigate and manage your condition. This leaflet explains our service, who will be involved in your care and the support available.

Confirming your identity

Before you have a treatment or procedure, our staff will ask you your **name** and **date of birth** and check your **ID band**. If you don't have an ID band we will also ask you to confirm your address.

If we don't ask these questions, then please ask us to check.
Ensuring your safety is our primary concern.

About us

We have been providing specialist care for patients with neuroendocrine tumours since the early 1990s and became a European NET Society (ENETS) accredited Centre of Excellence in 2012. Over this time we have managed thousands of patients with these relatively rare tumours.

Care is provided by King's College Hospital and Guy's and St Thomas' NHS Foundation Trusts (as part of King's Health Partners), Kent Oncology Centre and Hampshire Hospitals NHS Foundation Trust.

We cover a population of around four to five million people and see patients from South East London, Kent, Hampshire and Sussex, as well as other areas of the country.

We care for patients with neuroendocrine tumours arising from many different organs. A number of our clinics at King's College Hospital are held in Liver Outpatients, but this does not mean that you have a problem with your liver.

Who will provide my care?

You will be cared for by the NET team. This is a multidisciplinary team (MDT) made up of healthcare professionals who have vast experience of working with patients with neuroendocrine tumours.

Your consultant (senior doctor) has overall responsibility for your care and works closely with the rest of the team to ensure you receive the best care possible.

Which consultant cares for you depends on the treatment you are having. When you have a different treatment, you may see different members of the team, but we all work very closely together.



Your care team

Your team may include healthcare professionals from a number of different specialties, such as:

- oncology
- hepatobiliary surgery
- gastroenterology
- cardiology
- cardiothoracic surgery
- biochemistry
- nuclear medicine
- radiology
- nuclear medicine therapy
- interventional radiology
- thoracic surgery
- respiratory medicine
- endocrinology
- histopathology
- dietetics

Your key worker/clinical nurse specialist (CNS)

Wendy Martin and Elmie Cananea: kch-tr.NETCNS@nhs.net

Coming into hospital for investigations or treatment can be a difficult and uncertain time for you and those close to you.

We will give you a key worker to make sure you get the best care and support.

Your key worker will be a clinical nurse specialist (CNS) who specialises in caring for people with neuroendocrine tumours.

We will give you the name and contact details of your key worker at your first clinic appointment with us. Contact them if you have any questions about your care.



Your key worker will:

- answer your questions and offer you written information about your cancer, investigations, treatments or symptoms
- ensure your tests and investigations run smoothly and efficiently, including arranging scans and appointments
- offer emotional and practical support and advice
- help you to manage any symptoms or treatment side effects
- help you to get extra support at home
- find you support and information to address financial worries
- offer support to friends, relatives and partners
- refer you for specialist supportive care and complementary therapies.

Research

We are part of King's Health Partners, an Academic Health Science Centre that focuses on research and putting what we learn into practice for the benefit of patients. This includes carrying out clinical trials of treatments for neuroendocrine tumours.

We may invite you to take part in a study or trial during your treatment. We will fully discuss this with you and it will be entirely up to you whether you get involved. You can decide not to take part. This will not affect your treatment in any way.

Our research projects

King's College Hospital NET unit has an active research programme dedicated to furthering the understanding of what causes NETs, how it grows, how it can be detected earlier and also for the development of new therapies.

Quality of life research in NET patients: This examines the effect of different therapies on patients' quality of life, including therapy side effects.



Ex-vivo models of neuroendocrine tumours: This aims to develop new ways of growing NETs in artificial environments to understand how they grow and which medical therapies work best.

Nutrition in neuroendocrine tumours: This looks at the number of patients with malnutrition as a secondary effect of their tumour and after therapy.

If you wish to donate to the research funds please ask your consultant or Clinical nurse specialist.

Contact us

NET team, including clinical nurse specialist (CNS)

Tel: 020 3299 3854

Email: kch-tr.NETTEAM@nhs.net

Mobile: 07854246603

Consultants/secretaries

Dr. Srirajaskanthan and Prof. Ramage

Tel: 020 3299 3255

CNS secretary (regarding clinic appointments and investigations)

0203 299 9000 ext. 33368.

Consultant clinical oncologists/secretaries

Tel: 020 7188 4249

Guy's oncology appointments

Tel: 020 7188 3755

Nuclear medicine department

For patients having investigations or nuclear medicine treatment

Tel: 020 3299 3153



More information

Neuroendocrine Tumour Patient Foundation

www.netpatientfoundation.org

Living with NETs leaflet

Information on emotional self help

www.kcl.ac.uk/ioppn/depts/pm/research/imparts/Quick-links/Self-Help-Materials/Living-with-Neuro-Endocrine-Tumour.pdf

King's NET patient web page

www.kch.nhs.uk/service/cancer/cancer-types/neuroendocrine

Sharing your information

We have teamed up with Guy's and St Thomas' Hospitals in a partnership known as King's Health Partners Academic Health Sciences Centre. We are working together to give our patients the best possible care, so you might find we invite you for appointments at Guy's or St Thomas'. To make sure everyone you meet always has the most up-to-date information about your health, we may share information about you between the hospitals.



PALS

The Patient Advice and Liaison Service (PALS) is a service that offers support, information and assistance to patients, relatives and visitors. They can also provide help and advice if you have a concern or complaint that staff have not been able to resolve for you. The PALS office is located on the ground floor of the Hambleton Wing, near the main entrance on Bessemer Road - staff will be happy to direct you.

PALS at King's College Hospital, Denmark Hill, London SE5 9RS

Tel: **020 3299 3601**

Email: **kch-tr.palsdh@nhs.net**

You can also contact us by using our online form at

www.kch.nhs.uk/contact/pals

If you would like the information in this leaflet in a different language or format, please contact PALS on **020 3299 1844**.



