The Specialist Centre for Head and Neck Cancer
Information for patients and carers
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1. Introduction

Being diagnosed with cancer can be a difficult time for you and those close to you. This leaflet gives you an overview of the expert care you can expect to receive as our patient at University College London Hospital NHS Foundation Trust (UCLH), and introduces different types of healthcare professionals you may meet along the way.

Please note, this leaflet is not designed to explain your diagnosis. You should have been given additional written information on this. If you are not clear about your diagnosis or have any questions, please ask your nurse or doctor.

2. Head and Neck Cancer Service at UCLH

In autumn 2015 UCLH became a specialist centre for complex or rare specialist surgery of head and neck cancer for the people of north and east London and west Essex. This means that patients continue to have some of their cancer treatment at their local hospital but may be seen at UCLH for surgery or other specialist treatment.

We work closely with local hospitals, GPs and other local services to ensure your care continues smoothly between different hospitals.
We are one of the largest head and neck centres in the country bringing together ear, nose and throat (ENT) and maxillofacial head and neck oncology services. We provide expert medical and nursing care, as well as anaesthetic and rehabilitative services. Some of our specialist services include:

• Reconstructive surgery – we offer a range of surgical procedures for reconstruction following cancer treatment to restore appearance and function.

• Pre-cancer screening – we use the latest diagnostic techniques to help detect early signs of cancer. We also screen for and treat conditions that could eventually turn into cancer.

• Minimally-invasive tumour resection - minimally invasive surgery is used when possible to remove tumours that are located near important areas. This allows patients to recover more quickly than they would with traditional, open surgery.

• Sarcoma of the head and neck – we provide surgical treatment for The London Head and Neck Sarcoma Service including major cases of skull base surgery.

• Clinical trials – we have a range of clinical trials available to our patients, pioneering new treatment approaches.

For details on the different services and types of treatments offered at UCLH, please see our website www.uclh.nhs.uk/headandneckcancer
3. Specialist Multi-Disciplinary Team (MDT)
A multi-disciplinary team is a team of professionals who will be caring for and supporting you at UCLH. This team consists of experts in different areas of medicine and care, such as doctors, nurses, dietitians, physiotherapists and occupational therapists.

**It is important that you understand what your treatment involves. Please feel free to ask questions about any part of your care plan and we will do our best to give you clear answers.**

We will also give you written information about your diagnosis and treatment to support the discussions you will have with members of our team. If there is anything you do not understand or if you have any questions about the written information, please ask us.

You may find it helpful to write down any questions you would like to ask us before your appointment. This may help you to remember everything. We also strongly encourage you to bring a relative or friend with you to the clinic. They can help you remember what has been discussed and offer you support.

4. Members of the MDT

**Consultant surgeons**
You may need surgery as part of your cancer treatment. The surgeon treating you will be a specialist in performing the type of surgery you need.

**Consultant medical and clinical oncologists**
Oncologists are specialists in the chemotherapy or radiotherapy treatment used to treat your type of cancer.
Clinical nurse specialists (CNSs) in cancer care
Clinical nurse specialists are qualified nurses with specialist training and extensive experience in treating patients with your type of cancer. They offer advice and support throughout your diagnosis, treatment and follow-up.

Your CNS may also act as your key worker during your treatment, which means they are a consistent point of contact for you, your family and any professionals involved in your care. They can be contacted between 08:00 and 16:00, Monday to Friday (excluding Bank Holidays).

CNS name: ____________________________________
Contact Number: ____________________________________

Consultant radiologist
Consultant radiologists are specialists in examining and interpreting X-rays, CT scans, MRI, bone scans and other diagnostic tests to diagnose disease.

Consultant histopathologist
Consultant histopathologists are specialists in examining tissue and cells taken from biopsies and other diagnostic tests to diagnose disease and confirm the type of cancer.

Speech and language therapist
The speech and language therapist will help you if you have problems with your communication (speech and voice) and with swallowing (eating and drinking).

Dietitian
The dietitian will help you maintain your nutrition by assessing, advising and monitoring your food intake. It may be necessary for you to have a feeding tube as part of your treatment and, if so, the dietitian will give you further information.
Other members of the MDT (as applicable)
There are other specialists such as physiotherapists, occupational therapists, social workers and research nurses who are part of the extended MDT. You may be referred to these specialists if appropriate.

For staff profiles please see www.uclh.nhs.uk/headandneckcancer

5. The head and neck MDT meeting
The MDT meets every week to discuss the diagnosis and treatment plan of individual patients. They ensure that each patient is given the same high standard of care and has the most appropriate investigations and treatment.

6. What happens after the MDT meeting?
After your case has been discussed in the MDT meeting, the recommendations are recorded in your notes. It is likely that an appointment will be made with your consultant and/or CNS to discuss this further, or you may be called to have further investigations. You may bring a friend or relative with you to any of these appointments.

In some cases it may be more appropriate to refer you to another specialist team, in which case we will contact you to let you know.
7. Holistic Needs Assessment (HNA)
We know that having investigations and treatment can affect your quality of life in different ways. We will therefore offer you a ‘holistic needs assessment’ (HNA). This involves questions relating to your general wellbeing, social situation and support network. It will also help identify any particular issues or concerns you may have, to ensure we are offering you the most appropriate care plan. If you haven’t been offered an HNA and feel it would be helpful, please speak to your key worker.

8. Treatment options
There are many treatment options available at UCLH for patients with head and neck cancers. The type of treatment you are offered depends on the type of cancer you have. Your doctor will discuss with you the best treatment options for you.

Research and clinical trials
As a large research centre, UCLH runs a range of clinical studies aimed at improving knowledge, treatment and outcomes in head and neck cancer. Your doctor will talk to you about whether you’re eligible for a research study.

If you choose to participate, you will be supported by a research nurse.

A clinical trial is a carefully designed research study looking at the effects of a procedure or a treatment. A trial aims to find out if the treatment or procedure:

- is safe
- has side effects
- works better than the treatment that is currently used
- helps you feel better.
A trial can be carried out in the following areas:

- **Screening** – to find ways of detecting cancer at an earlier stage.
- **Diagnosing cancer** – looking at new tests or scans that detect cancer in a better way.
- **Treatments** – treatments with new drugs or new combinations of drugs, other types of treatment such as radiotherapy or surgery, or new ways of giving treatment.
- **Controlling symptoms or side effects** – reducing these by using new drugs or complementary therapies.
- **Genetics** – to help learn more about the role genes play in cancer.

We have a number of clinical trials in head and neck cancers looking at different treatment approaches. Your doctor may invite you to take part in a trial if you meet its criteria, and explain what it involves.

It is entirely up to you whether or not you wish to get involved. If you decide not to participate, or if you choose to withdraw at any time, this will not affect your treatment or care in any way.

9. **Communicating with you and your GP**

Your GP will always be informed of your diagnosis, treatment and care. You will also be automatically copied into these letters.

If there is anything you do not understand in the letters that you receive, please bring them with you to your next appointment and we will be happy to discuss any questions you may have.

10. **Out-of-hours advice**

If you are currently receiving treatment and need to speak to someone out of hours because you have a medical emergency, please go to your local Emergency Department (A&E) or contact your GP.
11. The Macmillan Support and Information Service
The Macmillan Support and Information Service is based on the ground floor of the University College Hospital Macmillan Cancer Centre, Huntley Street. It provides a relaxed and informal space where patients and their families and friends can ask questions and talk through their concerns with specialist staff. The team offers support at any stage of a patient’s experience with cancer.

You can access a range of information resources, including leaflets and booklets. Patients can also be referred onto appropriate services, such as complementary therapy, the wig service, dietitian, welfare and benefits advisers, and the psychological and emotional care team.

There is a programme of supportive activities on offer to help patients manage the effects of their treatment and meet other people who have shared similar experiences.
You don’t need an appointment to visit the service, and the team ensure that visitors are seen as quickly as possible.

Address: University College Hospital Macmillan Cancer Centre, Ground Floor, Huntley Street, London WC1E 6AG

Telephone: 020 3447 8663

Email: supportandinformation@uclh.nhs.uk

Opening hours: 09:00 to 17:00, Monday to Friday

12. Patient Advice and Liaison Service (PALS)
PALS is a patient-friendly, easy-to-access service designed to provide a personal contact point to assist patients, relatives and carers. If you have a problem that you have been unable to resolve, PALS can help you.

The University College Hospital PALS office is located on the ground floor of the main hospital building and is open from 09:00 to 16:00, Monday to Friday.

Telephone: 020 3447 3042

Email: PALS@uclh.nhs.uk
13. The interpreting service
This service is for patients who speak little or no English, or are deaf or hard of hearing and need communication support.

We usually use telephone interpreting which ensures that over 170 languages and dialects are readily available 24 hours a day, 365 days a year. We recognise that there will be occasions when telephone interpreting is not suitable. If needed, your clinical team will arrange a face-to-face interpreter, British Sign Language (BSL) or DeafBlind Communicator.

Please let your clinical team know if you need an interpreter. If you are coming for your treatment from another hospital, please ask your local team to let us know in advance that you need a face-to-face interpreter.

14. Travel information
We recommend that you travel to University College Hospital and the Cancer Centre by public transport. There are no allocated parking facilities at either site.

How to get here
Getting to the Cancer Centre by bus:

- Tottenham Court Road – Northbound (Warren Street station) – no’s 10, 73, 24, 29, 134
- Gower Street – Southbound (University Street) – no’s 10, 24, 29, 73, 134
- Euston Road – no’s 18, 27, 30, 88
By tube:

- Warren Street (Northern / Victoria Lines)
- Euston Square (Circle / Hammersmith & City / Metropolitan Lines)

For further information about travelling on the tube, please visit Transport for London (TfL) at www.tfl.gov.uk

Blue Badge
Patients with a Blue Badge will need to apply for a parking dispensation. For up-to-date information on this, please see our website www.ulch.nhs.uk

Congestion Zone
Please be aware that the Cancer Centre and University College Hospital are in the congestion charge zone. For details of how to pay, contact Congestion Charging at Transport for London (TfL) on 0845 900 1234 or at www.cclondon.com

If you are a Blue Badge holder, please refer to the website for details on how to register.
Hospital transport
Patients who are medically unfit to travel by any other means, may be eligible for hospital transport. Patients are given an assessment about their clinical condition and mobility by a member of a nurse-led assessment team to see if they qualify.

If you think you are eligible and wish to be assessed, you can contact the transport assessment team on 020 3456 7010 as soon as you receive your appointment.

If you need help to apply for hospital transport, a friend, relative or carer can call on your behalf.

Can I claim a refund of my hospital travel costs?
If you are travelling to the hospital for NHS treatment under the care of a consultant, you may be able to claim a refund. You can make a claim if you receive any one of the following benefits:

• Income Support
• Pension Credit – Guarantee Credit only
• Income based Jobseekers Allowance
• Income Based Employment and Support Allowance
• Working Tax Credit (exemption card)
• Child Tax Credit (exemption card)
• NHS low Income Scheme (HC2/HC3 form)
How do I make a claim?
Collect a completed Attendance Slip from your clinic/ward reception area and take the documents below to the Cashiers Office on the ground floor of the hospital:

• Attendance slip
• Proof of your travel costs i.e. tickets, travel receipts or Oyster Card
• Proof of your entitlement that you are in receipt of one of the qualifying benefits.

The claim will be validated by the cashier and if the documentation is correct, payment will be made on the day. All travel costs will be calculated based on the cheapest form of transport.

If you have travelled by car, petrol costs are calculated on a “pence per mile” rate, based on the distance between the hospital and your home address.

For more information please visit our website www.uclh.nhs.uk

15. Additional Information

Free prescriptions
As a cancer patient you are entitled to free prescriptions. Simply pick up a FP92A form from your GP surgery. Then complete the form and ask your GP, hospital doctor or clinical nurse specialist (CNS) to sign it.

Financial help
Some patients are entitled to financial help and benefits. Please ask your clinical nurse specialist if you think you may be eligible, pop into the Macmillan Support and Information Service, or phone the Macmillan helpline on 0808 808 00 00 (open between 09:00 and 20:00, Monday to Friday).
16. Other sources of information

Please also see our web page at www.uclh.nhs.uk/headandneckcancer for an up-to-date list of sources of information.

Please note: UCLH cannot guarantee the quality of the information or advice provided by outside organisations and charities.

**Macmillan Cancer Support**
Provides support and information on the practical, social, and financial effects of cancer for patients and those close to them.

www.macmillan.org.uk
0808 808 00 00

**Cancer Research UK**
Provides information about cancer, clinical trials and research.

www.cancerresearch.org.uk
0808 800 4040

**Changing Faces**
UK-based charity giving support and information to people with disfigurements to the face, hands or body, and their families.

www.changingfaces.org.uk
info@changingfaces.org.uk
0845 4500 275 or 0207 391 9270

**Healthtalk.org**
Information and support for a range of health issues from seeing and hearing people’s real life experiences.

www.healthtalk.org
17. Contact details

University College Hospital
235 Euston Road, London NW1 2BU

Switchboard: 020 3456 7890 or 0845 155 500

University College Hospital Macmillan Cancer Centre
Huntley Street, London WC1E 6AG

(There is no additional service charge for using an 0845 number. The cost is determined by your phone company’s access charge.)

Website: www.uclh.nhs.uk