

# National Hospital for Neurology and Neurosurgery

## Multidisciplinary team clinic

Huntington's Disease Service



**If you would like this document in another language or format, or require the services of an interpreter, contact us on 020 3448 3420. We will do our best to meet your needs.**

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This booklet has been written by the Huntington's Disease Service at the National Hospital for Neurology and Neurosurgery. It is intended for patients, their families and/or carers who have been referred to our service or are under the care of the team here.

The aim of the booklet is to provide information about the Multidisciplinary Huntington's Disease Clinic, which is held twice a month at this hospital.

We hope that it will answer some of the questions that you may have about what to expect.

### **What is the Multidisciplinary Team Clinic?**

This is a specialist clinic for people (and their families or carers) who have or are at risk of having Huntington's Disease.

We see people for the following reasons:

- For pre-symptomatic genetic counselling and testing;
- For pre-natal genetic counselling and testing;
- For management of symptoms;
- To give advice, information, social and emotional support; and

- To give information about research and the opportunity to take part in current research projects in Huntington's disease, if appropriate.

### **Who will I see in clinic?**

There is a whole team of people who work as part of the clinic. You may see one or more of them at your appointment depending on you or your needs.

The team consists of:

- Consultant Neurologists
- Consultant Neuropsychiatrist
- Consultant Clinical Geneticist
- Nurse Consultant
- Clinical Research Fellows
- Specialist Nurse
- Huntington's Disease Association Specialist Advisers
- Research team
- Secretary
- Clinic Co-ordinator

You may also meet other outpatient staff in the clinic including the clinic nurses, receptionists, patient transport

officer, pharmacists and phlebotomist (the person who takes blood).

We want you to get the most out of your appointment in the clinic and this may mean that you see a number of team members. However, we do not want your clinic appointment to be too much for you, if you would rather just see one or two people please let us know.

### **How long will my appointment take?**

The amount of time you spend in clinic will depend on who you see and what issues you need to discuss.

A new patient appointment with one of the Consultants usually takes around 45-60 minutes. You may also need to see one of the Huntington's Disease Association Care Advisers, the Specialist Nurse or both. And you may decide you would like to speak with one of the research team.

## **What should I bring to my clinic appointment?**

You will need to bring with you:

- An up-to-date list of all medicines you are taking, including over the counter and complementary medicines;
- Your current contact details – address and telephone number;
- Contact details of your next of kin or anyone else involved in your care, such as your GP or carer.

This allows us to keep you informed and ensures our information is correct.

## **Who can come with me to my appointment?**

You are welcome to bring a family member, friend, carer, or health or social care professional such as a social worker or community nurse with you to your appointment.

## **How often will I need to come back to clinic?**

This will depend on you. Some people come back once a year others come more often.

If you are started on a new medication in clinic, we may need to see you again fairly soon in order to see how the medication is working and check that it suits you.

Also, if you are having difficulties, you may need to come back to clinic more frequently.

## **Will I be referred to anyone else in the hospital?**

There are a number of other services within this hospital that you may be referred to. These include Speech and Language Therapy, Physiotherapy, Occupational Therapy, the Dietitian and Psychology.

## **What if I have more questions before I come to clinic?**

You can telephone the HD Clinical Nurse Specialist on 020 3448 3776 or you can ask someone to telephone on your behalf. Alternatively, if you are already linked to one of the Huntington's Disease Association Specialist Advisers you can speak to them about the clinic.

The NHNN Multidisciplinary Huntington's Disease Clinic is featured in the Department of Health Good Practice Guide for Care of People with Long-Term Neurological Conditions. You can view this through the Department of Health website:

([www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/LongTermConditions/BestPractice/fs/en](http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/LongTermConditions/BestPractice/fs/en))

### **For further information**

If you would like further information about any ongoing research opportunities please visit:

 <http://hdresearch.ucl.ac.uk/current-studies>

 0207 611 0126

Huntington's Disease Association

Head Office: 0151 331 5444

Website: <http://www.hda.org.uk>

Huntington's Disease Youth Organisation

Website: <http://hdyo.org>

General enquiries: [info@hdyo.org](mailto:info@hdyo.org)

## Contact details

Huntington's Disease Service

Box 104

National Hospital for Neurology and Neurosurgery

Queen Square

London

WC1N 3BG

Direct line: 020 3448 3776

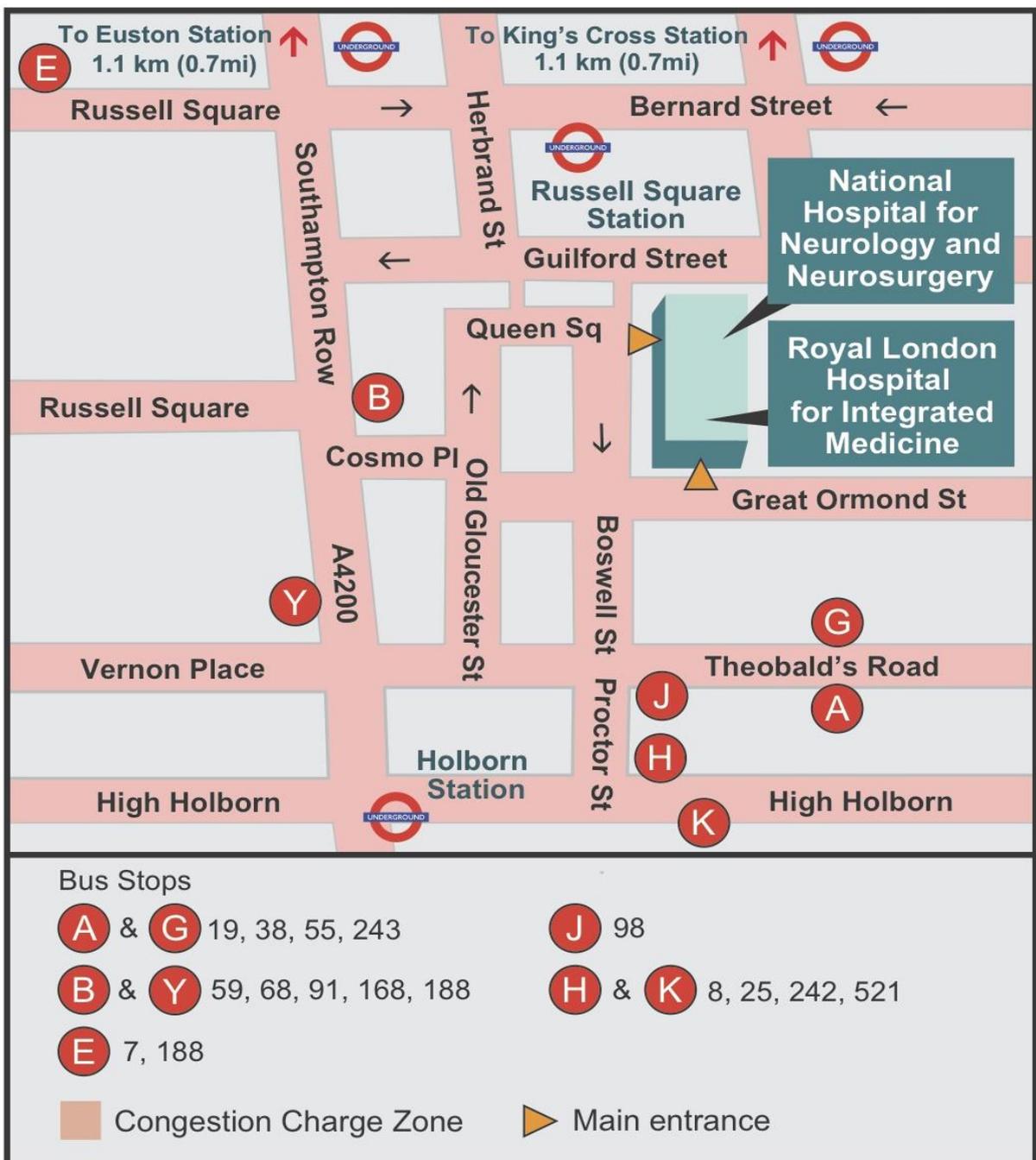
HD team secretary: 020 3448 3420

HD Clinical Nurse Specialist: 020 3448 3776

Fax: 020 3448 4784

Website: [www.uclh.nhs.uk/nhnn](http://www.uclh.nhs.uk/nhnn)

## How to find us



## Space for notes and questions

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