

Peninsula Clinical Genetics

You, or your child, have been referred to Clinical Genetics. This leaflet provides information about the Clinical Genetics Service and will give you an idea about what will happen at your clinic visit.

Peninsula Clinical Genetics

The Peninsula Clinical Genetics Service is hosted by Royal Devon and Exeter NHS Foundation Trust and provides Clinical Genetics care to the population of Devon and Cornwall. There are also offices in Plymouth and Truro.

The clinical team consists of Consultants, Specialty Registrars (qualified doctors training to become consultants in Clinical Genetics), Genetic Counsellors / Nurses and trainee Genetic Counsellors. Genetic Counselling is the process of giving information about genetic conditions and discussing possible options; it is not the same as general counselling.

Why have I been referred to Clinical Genetics?

There are several reasons why your doctor may feel that referral to the genetics clinic is appropriate, for example:

- Your doctor would like help in making a diagnosis for you, or your child.
- You, or a member of your family, have a condition that may be hereditary.
- You have requested information about a genetic condition.
- To discuss screening or testing for a genetic condition.

What will happen next?

- You may be sent a family history sheet. This will provide us with some basic information that will help us to provide an assessment when we see you in clinic. Please complete as much of it as you can and return it to us as soon as possible. Don't worry if you cannot complete all of the information.
- We will not contact your relatives without your consent. We may need consent from your relatives to review their medical records relating to the genetic condition in your family. If we do, we will give you a consent form to pass on to them.
- Depending on the reason you were referred, we might arrange some other investigations before seeing you. If we do this we will write to you to inform you.
- Our waiting lists can be quite long so it may be several months before you next hear from us.
- When you are nearing the top of the waiting list you will be sent a 'Partial Booking' letter. This will invite you to telephone our Appointments Clerk to make an appointment. Please ring within 2 weeks.

YOUR CLINIC APPOINTMENT

Where is the clinic held?

Clinics are held at all the main hospitals, and many community hospitals, across Devon and Cornwall. You will usually have an appointment at your local hospital.

Parking at most hospitals is difficult, so if you are travelling by car please allow plenty of time to find a parking space. Some hospitals have a Park and Ride service - details are on the hospitals' websites.

How long will my appointment last?

Appointments usually last 45 minutes or an hour, depending on the clinic, so there should be plenty of time. If there is insufficient time to deal with all of the issues we will arrange another appointment for you.

If you are unable to attend please let us know as soon as possible so that the appointment can be offered to someone else.

Who will I see at the clinic?

- You will see a Genetic Counsellor / Nurse, Clinical Genetics Consultant or Specialty Registrar. Who you see will depend on the reason you were referred.
- The name of the person running the clinic, and their job title, will be on your appointment letter.
- Sometimes people are seen by two members of the team.
- Our department hosts Trainee Genetic Counsellors. You may be seen by a Trainee Genetic Counsellor. Trainees see people alongside another staff member or alone in their final year. All trainees work under close supervision.
- Occasionally a doctor or health care professional from another specialty is present to gain experience in Clinical Genetics. If you do not want somebody else there please let us know.
- We are involved in training medical and nursing students from University of Exeter Medical School and Plymouth University. If you do not wish to have a student present please let us know by telephone in advance, or when you arrive at the clinic.

What happens at the clinic?

- The genetics professional will discuss the reasons for your referral and go over your personal and family medical histories.
- If appropriate, you may be offered a physical examination.
- You may be asked for consent for us to take photographs of you or your child. These form part of your/their confidential medical record.
- Investigations such as blood tests, X-rays or scans may be arranged, if necessary.
- Genetic Testing is not always offered at the first appointment. Some conditions require a longer counselling process, or require us to gather further information before a test.
- There will be plenty of opportunity to ask questions.
- We actively participate in national and international genetics research studies; if there is a research study that is applicable to you this will be discussed. You will have a choice whether or not to participate.

What happens next?

- We will send you a letter summarising the discussion that has taken place.
- A copy of this letter will be sent to your GP and any other specialists involved in your care (unless you ask us not to do so).
- If anything remains unclear after receiving your clinic letter, or if you have further questions related to your condition or family history, please contact the person you saw.

How many appointments will I have?

It will depend on the reason for your referral. It will be discussed with you and be written in your letter.

- Many people will only need one appointment with either a Genetic Counsellor/Nurse or a Consultant/Specialty Registrar.

- Some people are offered an initial appointment with a Genetic Counsellor/Nurse to gather more background information, have initial discussions or initial tests before seeing a doctor at a subsequent appointment.
- Some people will be offered further follow-up appointments.
- Some people will be referred to another specialist for on-going care, or back to their GP.

What should I do if I am unhappy with my visit to the clinic?

We hope that you will find your visit to the genetics clinic useful. However, if you have any comments or complaints about any aspect of the service please write to the person you saw, the Lead Clinician or the Cluster Manager at:

Peninsula Clinical Genetics
Royal Devon and Exeter Hospital (Heavitree)
Gladstone Road
Exeter
EX1 2ED

OR

The Patient Advice and Liaison Service at:
The PALS Office
Royal Devon and Exeter Hospital (Wonford)
Barrack Road
Exeter
EX2 5DW

Tel: **01392 402093**

Email: **rde-tr.PALS@nhs.net**

The Trust cannot accept any responsibility for the accuracy of the information given if the leaflet is not used by RD&E staff undertaking procedures at the RD&E hospitals.

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