

Neurofibromatosis type 1 transition information

This leaflet explains more about the transition process offered in the neurofibromatosis (NF) service. If you have any further questions, please speak to a doctor or nurse caring for you.

What is the transition process?

Transition is the move from paediatric to adult clinics. It is a time for planning and looking to the future. For people with neurofibromatosis type 1, it is important to ensure that you are involved, prepared and understand the changes. During this time you will gradually have your care moved from the paediatric clinics to the adult clinics within the neurofibromatosis team.

When does transition start?

From the age of 14, the paediatric team will help you to prepare for the transition process. They will do this by supporting you in setting some helpful goals that you can aim to achieve by the time you reach 16 years. During each clinic visit, the aim will be to set new goals with support from the clinical nurse specialist so that you can become more independent.

Where?

The paediatric and adult clinics are both based in the neurofibromatosis department at Guy's Hospital. The paediatric and adult clinics may be on different days. The transition clinics happen alongside the paediatric clinics and you will have the opportunity to meet others of similar ages who also have neurofibromatosis.

Who will I see?

During your transition appointments you will see your paediatric NF doctor, orthoptist (a specialist doctor who measures your vision) and clinical nurse specialist. You will also have the opportunity to meet with the adult clinical nurse specialist.

What will I do?

The plan of the transition process is to support you in setting up goals to become more independent in managing your neurofibromatosis. The clinical nurse specialist will support you in setting these goals with you and your parents.

It is helpful if you can think of some goals before you attend the clinic and a list of any questions you would like to ask us. You will also have the opportunity to see us on your own and then your parents can join the consultation afterwards.

Contact us

If you have any more queries please contact the nurse advice line on **t:** 020 7188 9979, Monday to Friday, 9am-4.30pm.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit **w:** www.evelinalondon.nhs.uk/leaflets

Evelina London Medicines Helpline

If you have any questions or concerns about your child's medicines, please speak to the staff caring for them or contact our helpline.

t: 020 7188 3003 10am to 5pm, Monday to Friday **e:** letstalkmedicines@gstt.nhs.uk

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk
t: 020 7188 3514 (complaints) **e:** complaints2@gstt.nhs.uk

Language and accessible support services

If you need an interpreter or information about your care in a different language or format, please get in touch:

t: 020 7188 8815 **e:** languagesupport@gstt.nhs.uk

NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

t: 111 **w:** 111.nhs.uk

NHS website

Online information and guidance on all aspects of health and healthcare, to help you take control of your health and wellbeing.

w: www.nhs.uk

Get involved and have your say: become a member of the Trust

Members of Guy's and St Thomas' NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, and to become a member:

t: 0800 731 0319 **e:** members@gstt.nhs.uk **w:** www.guysandstthomas.nhs.uk/membership

Was this leaflet useful?

We want to make sure the information you receive is helpful to you. If you have any comments about this leaflet, we would be happy to hear from you, fill in our simple online form, **w:** www.guysandstthomas.nhs.uk/leaflets, or **e:** patientinformationteam@gstt.nhs.uk

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