

# Children's spinal cord clinic

This leaflet gives information about the spinal cord clinic at the Evelina London Children's Hospital.

If you have any further questions please speak to a doctor or nurse caring for you.



### What is the children's spinal cord clinic?

This is a specialist clinic where you and your child have the opportunity to meet the team who will be involved in your child's care.

We are here to offer advice and support for all aspects of your child's health and wellbeing.

#### Members of your team

- A consultant neurologist who will monitor your child's brain and nerve development.
- A consultant neurosurgeon from King's College Hospital who will monitor the results of any neurosurgery already performed.
- A consultant paediatrician (children's doctor) who will look after your child's bladder and bowel.
- A specialist physiotherapist who will assess your child's strength and movement. Advice about equipment and other treatments to help your child may be given. Orthopaedic surgeons (bone and joint doctors) may be asked to review your child.
- Specialist nurses who are available to answer any questions you or your child may have between appointments and help with other practical issues.

The team cooperates and shares information with your local services so your child receives the best possible care, with minimal disruption to their everyday lives.

#### Who can use the service?

Any child who has a diagnosis that affects their spine can be seen in the clinic.

Your child will usually be referred to our service by their consultant neurosurgeon, however, we will accept referrals from any doctor involved in your child's care such as your child's GP, paediatrician or paediatric neurologist. We see children between the ages of 0 to16 years.

The first appointment will be sent out to you by post and you can expect to see us within three months of referral. In the first four years of life your child is usually seen every six months. After this they will be seen once a year. When your child is ready to move to adult services we will support their move to make this as smooth as possible.

#### Where do I need to go?

The clinic is run in Ocean, the Outpatient Department on the ground floor of Evelina London Children's Hospital.

When you arrive please register your child at the reception.

#### What can I expect?

We may need to carry out some investigations so please allow up to four hours at the hospital on the day of your child's appointment.

The investigations may include:

- an ultrasound which will take a picture of the kidneys, bladder and hips
- an X-ray of your child's spine or hips
- blood tests
- bladder tests.

Not all tests will have to be repeated at each appointment.

We will discuss the reasons for these tests with you on the day and let you know where to go.

## What do I need to bring with me?

Please bring:

- your child's red health book
- recent medical reports or letters you might have
- any medicine your child may be taking
- mobility aids or catheters.

There are a number of shops and cafes on site but you may want to bring your own food and drink.

#### Useful sources of information Shine

Charity that provides information on hydrocephalus and spina bifida. **w:** www.shinecharity.org.uk

#### **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, Monday to Friday, 10am-5pm 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

#### **Contact us**

If you have any questions or concerns about this clinic please contact the secretary, **t**: 020 7188 7188 ext. 88533 (Monday to Friday, 9am to 5pm), or the specialist nurse, **t**: 020 7188 4592.

To change a clinic appointment please call the appointments centre on t: 020 7188 4000 or email us on e: paediatricappointment@gstt.nhs.uk

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

#### 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

Leaflet number: 4187/VER2

Date published: January 2019 Review date: January 2022 © 2019 Guy's and St Thomas' NHS Foundation Trust A list of sources is available on request



**NHS Foundation Trust**