

Bladder Exstrophy Psychology Service

We are a highly specialist clinical psychology service for children and young adults with bladder exstrophy and/or epispadias conditions. There is research evidence to demonstrate that with good support children and young adults with these conditions do extremely well. In the UK psychological support is available for all children with bladder exstrophy and/or epispadias and their families. This is provided by Clinical Psychologists at both Royal Manchester Children's Hospital and Great Ormond Street Hospital. We work closely with the Consultant Paediatric Urologists and Clinical Nurse Specialist's to provide joined up care for your child and family.

What is a Clinical Psychologist?

A clinical psychologist is someone who has studied behaviour and feelings at doctoral level. In our setting we use this knowledge to try to understand the problems that children and their families may be having, and suggest different ways of trying to help to bring about change. We also have assistant psychologists as part of our team. Assistant psychologists are psychology graduates who work under the supervision of a qualified clinical psychologist. The clinical and assistant psychologists with the Bladder Exstrophy Service have specialist knowledge of exstrophy and how health conditions can interact with emotions and behaviour.

What can we help with?

Living with any kind of physical health problem can throw up challenges, even if only from time to time. The types of things we often help with include:

- Helping families adjust to the initial diagnosis (time for parents to talk through their own thoughts/feelings about their child's condition and how they want things to be for their child's future).
- Finding ways for children to feel confident growing up with an exstrophy condition.
- Helping families make decisions about surgery and the timing of surgery to ensure the best outcomes for the child.
- Working with siblings to help them understand their brother or sisters exstrophy condition.
- Developing tailored toilet training plans with parents.
- Providing advice/strategies around helping children cope with catheterisation.

- Evidence based therapeutic intervention for symptoms of anxiety, low mood, low self-esteem, anger or behaviour difficulties.
- Developmental assessments.
- School liaison to address any worries around bullying or academic progress.
- Time to talk through any sexual health/relationship concerns and develop ways for young adults to feel confident in relationships.

Bladder exstrophy and epispadias are conditions that tend to throw up different challenges for children and their families at different ages/ developmental stages. These hurdles can be overcome and children can grow up to feel good about themselves and in charge of their lives. Psychology support doesn't just focus on times when things are tricky. We are keen to hear about the things that are going well for you and your child. Your experiences and tips can make a big difference to our understanding of what it's like to live with an exstrophy condition and we can then share this knowledge with other families to help them along the way.

How do I get to see a member of the Bladder Exstrophy Service?

A member of your medical team may ask you if you would like to be referred, or you can request psychological support yourself by talking to the medical team or contacting us directly. You can contact us on 0161 701 5683 or 0161 701 4514, Monday – Friday 9.00 am – 5.00 pm.

What will happen during an appointment with the psychology service?

We believe in forming a relationship with you and your child that continues throughout their care. As such, you will see us working with the medical team at routine clinic appointments and we try to meet with families during inpatient stays so that we can keep in touch.

We also offer individual appointments outside of the clinic settings and jointly with specific members of the medical team depending on what it is you would like help with. If your child is in hospital we may visit you on the ward. Otherwise, appointments are held at the Harrington Building, Royal Manchester Childrens Hospital (RMCH). The first appointment will usually last about one hour. Some appointments may last longer but we will tell you in advance if this is the case. Sometimes we ask you and your child to fill in some questionnaires to help us measure some of the difficulties you might be experiencing.

During the first session, we will talk about any current difficulties as you and your child see them. We also want to know about your family in general, your child's early development and about school. This will help us build up a picture of your child's current situation and the difficulties you are facing.

As well as being asked questions, you and your child can also ask questions if there is anything you are unsure about. At the end of the first session, we will discuss the types of things that might be helpful and develop a plan for support that is tailored to your family.

Car Parking

The Harrington Building is not situated within the main building of the Children's Hospital but is near to the Hathersage Road car park. This car park is pay on foot and is situated on the corner of Hathersage Road and Upper Brook Street. Further details can be obtained from the health professional responsible for your clinical care.

Help with Transport Costs

If you are receiving Income Support or Family Credit you are entitled to help with the cost of travelling to and from your appointments. If you are on a low income you may be entitled to help with your travelling costs. Please tell a member of staff if you think you may be entitled to help with travel costs.

Information Sharing

It may help us to talk to staff at your child's school or other professionals about the difficulties that are being experienced. We would not do this without your consent. After we have met, we send letters and reports to:

- The person who referred your child and to the your child's GP.
- The hospital doctors involved in your child's care.
- Your child's Community Paediatrician and other professionals as appropriate.

Access to Health Records

The Data Protection Act 1998 means patients (with a few exceptions) can see their health records.

Contact Us

Paediatric Psychosocial Department
Harrington Building
Royal Manchester Children's Hospital
Hathersage Road
Manchester M13 9WL
Tel: (0161) 701 5683/4514
Fax: (0161) 701 1885
E-mail: paediatric.psychosocial@mft.nhs.uk

You can normally contact the department between the hours 9.00 am and 5.00 pm, Monday to Friday. Outside these hours, or if the lines are busy, there is an answer phone available.

Please leave a message and we will return your call as soon as possible.

The Paediatric Psychosocial Department is not an emergency service. In emergencies please contact your GP, local accident and emergency department or for in-patient, the on-call Psychiatrist.

Suggestions, Concerns and Complaints

If you would like to provide feedback you can:

- Ask to speak to the ward or department manager.
- Write to us: Patient Advice and Liaison Services, 1st Floor, Cobbett House, Manchester Royal Infirmary, Oxford Road, Manchester M13 9WL
- Log onto the NHS Choices website www.nhs.uk - click on 'Comments'.

If you would like to discuss a concern or make a complaint:

- Ask to speak to the ward or department manager – they may be able to help straight away.
 - Contact our Patient Advice and Liaison Service (PALS) – Tel: 0161 276 8686 e-mail: pals@mft.nhs.uk.
- Ask for our information leaflet.

We welcome your feedback so we can continue to improve our services.

No Smoking Policy

Please protect our patients, visitors and staff by adhering to our no smoking policy. Smoking is not permitted in any of our hospital buildings or grounds, except in the dedicated smoking shelters in the grounds of our Central Manchester site.


For advice and support on how to give up smoking go to <http://www.nhs.uk/smokefree>.

Translation and Interpretation Service

It is our policy that family, relatives or friends cannot interpret for patients. Should you require an interpreter ask a member of staff to arrange it for you.

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