

## INFORMATION LEAFLETS FOR PARENTS / CARERS OF A CHILD

### BLADDER EXSTROPHY BLADDER CARE PRIOR TO CLOSURE



#### What is Bladder Extrophy?

Bladder Extrophy is a rare condition and occurs in approximately 1 in 50,000 births. It is an abnormality affecting the bladder, genitals and pelvis and is more common in boys than girls. It does not usually affect your child's normal development.

#### What causes Bladder Extrophy?

The cause of Bladder Extrophy is unknown, it arises very early in pregnancy at approximately 4-8.

#### What happens after birth?

Your baby will be managed in the maternity hospital until you are well and ready for discharge. At this stage your baby will be admitted to Our Lady's Children's Hospital for investigations. During your stay the Consultant Paediatric Urologist will discuss with you, your baby's condition and proposed management and will organise a kidney ultrasound. The urology Clinical Nurse Specialist and the ward staff will support and help you with bladder care and answer any questions you have, there are other families living with this condition, if you would like to meet with another family we will happily arrange it.

#### Bladder Management

**The bladder is open and exposed on the abdomen and must be dressed with a non-stick dressing which is changed at each nappy change.**

- The healthy bladder lining looks bright red/pink and moist.
- **Avoid** baby wipes/cotton wool/barrier creams on/near the bladder. Clean the surrounding skin with warm water and gauze only.
- Urine will leak freely from the exposed ureteric openings. The surrounding skin on the abdomen can become irritated.
- If you are concerned about the condition of the skin around the bladder speak to your GP/CNS. You may need emollients or steroid cream to treat the area.
- Due to the forward position of the anus it is important to keep poo away from the bladder as much as possible.
- You can use barrier cream **sparingly** on the bottom.
- We will teach you how to gently cleanse the bladder area and apply a non-stick dressing with each nappy change. This dressing is to protect the bladder and prevent the bladder lining sticking to the nappy.
- The dressing we use is **Adaptic Touch**. This is a non-stick silicone dressing. If these are not available you can use **Jelonet**, parafin gauze. If you run out of dressings, you may use saline soaked gauze until dressings are available.

- The exposed bladder is not painful. Crying is natural and normal and it actually promotes growth of the bladder.
- **Shallow bath only** (water at hip level). Do not immerse the bladder in water.
- You will continue this bladder management plan until your child has surgery to close the pelvic ring and the bladder. This surgery is performed in Manchester at around 6-9 months of age.

**Signs and symptoms to observe closely for:**

- The bladder lining can **bleed** quite easily. Do not be alarmed if you see blood on the nappy. This is a result of friction/rubbing and is very normal.
- Children with Bladder Extrophy have a high incidence of developing **inguinal hernias**. These appear as lumps/bulges in the groin when the baby cries. Contact the hospital-CNSp if you suspect this.
- **Polyps** may develop on the surface of the bladder; these will appear as raised bumps. Contact the hospital CNSp.

**Points to remember**

- Dressings are on prescription and available from your pharmacy. You are advised to link in with your local Public Health Nurse regarding supplies also.
- It is advisable to apply for your child's medical card as soon as possible. Bladder Extrophy is a long term condition which will require medical care into the future.
- Please contact us if you have any questions or concerns, we are happy to help.

For more information on Bladder Extrophy Management, please contact Urology CNS in Our Lady's Children's Hospital, Crumlin, Dublin.

**Contact Details:**

Phone 01 409 6100    Bleep 8686 / 8687

**Remember: Ask your nurse if you are unsure about anything about your child's care.**

**Additional instructions**


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