

## Royal Manchester Children's Hospital

## Information for Patients

# Coming in for Bladder Exstrophy Closure

This leaflet is for parents or carers whose baby is coming into the hospital to have their Bladder Exstrophy closed, and the bladder put back inside the tummy. We understand this can be a worrying time for families, so we designed this leaflet to help answer some of the questions you may have when preparing to come into the hospital.

## What happens before my baby has their operation?

There are a few things that need to be done to get your baby ready for their operation to ensure they are fit and well for the surgery.

### Consent

The operation is discussed with you in your out-patient clinic appointment, and often we will ask you to sign a consent form during this appointment. Consent is a legal requirement whereby a person with parental responsibility gives us permission to perform the surgery. The risks and benefits of the operation are discussed with you, and you will have an opportunity to ask questions before you sign the consent form. The signed form is then kept in your baby's medical notes ready to be checked on the day of the operation.

### Anaesthetist

Before the operation, you will meet the Doctor (Consultant Anaesthetist) who looks after your baby whilst they are asleep during the operation, and ensures they have the right pain relief when they wake up. The Anaesthetist will ask you questions about your baby's medical history, and if they have ever had an anaesthetic before. They will also talk to you about what happens on the day of the operation, what to expect, and give you the opportunity to discuss any worries or concerns you may have. You will be given an appointment, **usually the week before the operation**, to come to Ward 76 to meet with the anaesthetist and for your baby to undergo the other tests as described below.

### Pelvic CT Scan

As you already know, part of your baby's operation involves manipulating the bones to close the gap in the pelvis (pubic diastasis) at the front of their tummy. Closing this gap puts the bones back into the correct position, reducing the chance of any complications in the future. There is a special bone Doctor (Consultant Orthopaedic Surgeon) who will perform this part of the surgery whilst your baby is asleep. A special scan, called a CT, is performed the week before the surgery to help the

Orthopaedic Surgeon plan this part of the operation; it's a little bit like drawing a map of the bones.

Your baby needs to be very still for the test so we will usually ask you to keep them 'Nil By Mouth' (starved) for the scan and you will be provided with starving times for this alongside your appointment time. This is because, sometimes, if your baby is not still enough when we do the scan, we can give them some special medicine (sedation) to make them feel sleepy whilst we perform the scan.

You will be given an appointment, usually the week before the operation, to come to Ward 76 as a day case for this scan. Wherever possible, we will try to make this on the same day as the appointment with the Anaesthetist so you do not need to travel to the Hospital on separate dates the week before surgery, and all the pre-operative checks can be done on one day.

### Blood test

Often, babies need to have a blood test before a big operation to check they are fit and healthy, and because there is always a risk of losing some blood during the surgery and baby needing a blood transfusion. In order to ensure we have the correct blood ready for your baby, in case they need a top-up during the operation, we have to take a special blood test called a 'cross match'. This blood sample is taken on the same day that your baby has their CT Scan and sees the anaesthetist. A second sample is then sent the day before the surgery, once you are admitted on the ward.

### The day before

You will be asked to come to the hospital the day before your baby's surgery (usually a Sunday), and will be admitted to Ward 77 where you will stay overnight. The second blood test (cross match) will be taken on the day you come in, although the time it is taken can vary as it will be the on-call team who come to take the blood test.

Some families who live very far away from the Hospital, choose to arrange their own private accommodation so that they can stay in Manchester from the date of the CT Scan/anaesthetist appointment right up until they are admitted to Ward 77 the day before the surgery. This is entirely your choice, and the Hospital cannot provide any support in arranging this.

### Where do I stay?

We understand it is important for you to be able to be close to your baby and have somewhere to stay whilst you are away from home. When you are admitted to Ward 77 (the day before the operation) you will be able to stay in a parent bed next to your baby's cot.

When your baby returns from surgery, they will usually be admitted to the high dependency or intensive care unit. The unit is very busy and there are often lots of noisy machines, so they are unable to provide you a bed next to your baby's cot. However, they have separate parent accommodation for which you will be allocated a room and given a key, and you will be able to come and go from the unit to see your baby as you please.

Once your baby is well enough to go back to Ward 77, you will be asked to return the parent accommodation key, and you will again be provided a parent bed next to your baby on the Ward.

Whilst we always make every effort to provide you a cubicle on the ward (due to the length of time you are admitted), this is not always possible, and cubicles have to be prioritised for infectious patients. Therefore, even if you are allocated a cubicle at some point during your stay, there is a chance you will be moved back out into a 4 bedded bay if there is a clinical need for another patient to be in a cubicle.

Due to the COVID-19 Pandemic, we are swabbing all elective theatre patients before they are admitted to the hospital (you will be given appointments and instructions for this). All patients are also currently re-swabbed every 7 days whilst they remain an in-patient.

## What about parking?

There is a multi-storey car park on site (Hathersage). You are able to purchase a parking permit for £20 per week from the Cashiers Office, and after two weeks parking is free.

## What facilities are there?

There is a small parent's room with some basic kitchen appliances and a fridge, which you can use to prepare food and drink. Hot food and drinks need to be consumed within the parent's room due to health and safety, and it's important you label any food or drink stored in the fridge to ensure it is not thrown away or eaten by another parent/guardian.

There are no laundry washing facilities on the ward. If you are allocated a room at Ronald MacDonald House, then you will be allowed to use their laundry facilities, as well as the communal areas for cooking and eating.

Bedding and towels are provided by the ward, as well as food, drink and nappies for your baby although we ask you bring some of your baby's usual nappies from home where possible. If your baby is on a specially prescribed milk, please ensure you bring an initial supply from home, and inform the ward on admission who can arrange for a dietician to see you and order the milk to be delivered to the ward for the rest of your stay. The ward has two sterilisers which you can utilise if you choose to bring your baby's own bottles. If you are expressing breast milk, we have a limited number of breast pumps available, although you are also welcome to bring your own from home.

Due to the COVID-19 Pandemic, we are trying to reduce families using shared facilities around the Hospital. Therefore, you will not be able to access the parent's room whilst you are admitted. The ward is providing all hot meals, snacks and drinks to parents who are resident on the ward and you will order your food each day, and will be allowed to eat this at the bed space. There is a small Marks & Spencer food hall on the main Boulevard, and there is also a W.H.Smith within the Children's Hospital that you can access for any additional items. We ask that you observe social distancing at all times, and wear a mask which can be provided by the Hospital if necessary.

## What is Ronald MacDonald House?

Ronald MacDonald House is specially designed family accommodation funded by charitable donations. The House is situated opposite the main entrance to Royal Manchester Children's Hospital and is only accessible once you have been referred by the ward, the referral accepted, and a room allocated to you and/or your family. It is designed to allow families to be together whilst their children are in Hospital. If you would like close relatives to be able to utilise and stay at the Ronald MacDonald House, then you will need to ask the ward to complete a referral. Priority goes to those who live furthest from the Hospital and who are expected to be an in-patient for longer than two weeks.

Due to the COVID-19 Pandemic, Ronald MacDonald House has decreased capacity to house families. You can still ask to be referred but it is less likely that a room will become available whilst you are an in-patient.

## Can I have visitors?

One parent or guardian is allowed to stay overnight, but a second parent or guardian can have unrestricted visiting throughout the day in addition to the parent or guardian who is resident. Additional visitors are allowed during visiting hours (13:00-17:00 and 18:00-20:00), providing there are no more than 4 people at the bed space at any one time.

**Due to the COVID-19 Pandemic, there are strict visiting restrictions in place. This is to protect our patients, families and staff and minimise the chance of spreading infection. For the most up to date visiting rules, please ring Ward 77 on 0161 701 7700.**

## What should I bring with me into Hospital?

The days can feel long whilst you are in the hospital and finding alternative ways to settle and comfort your baby whilst you cannot pick them up and cuddle them can be challenging. We have come up with some ideas of what essentials to bring, although feel free to bring anything you feel will make you stay more comfortable.

- Some entertainment for **you** e.g. book, magazines, crosswords.
- Some age appropriate toys for your baby. Whilst we have some toys on the ward, any favourite toys from home or things that aid sleep (cot mobile or cuddly toy) can be helpful.
- A favourite blanket, or a blanket that smells like you, can sometimes be a comfort in the first few days, and can also be draped over the frame to keep little hands away from the operation site! We are able to provide blankets on the ward too, so it is not essential you bring your own, but some families prefer to.
- Electronics such as a phone and phone charger are important in keeping you connected with your family whilst you are on your own in the hospital. Some families also bring a tablet, iPad or laptop, to provide entertainment.
- Babies are often teething when they have their surgery due to their age, so some teething toys are always helpful as we are unable to provide these on the ward due to infection control.
- The ward can provide toiletries for your baby, but it is often a good idea to bring a baby toothbrush (if they have started using one) and toiletries for yourself.
- Whilst the mermaid bandages are around your baby's legs, they will not be able to wear clothing on their legs. However, once they are feeling a bit better after the surgery, they can start wearing clothes on their top half. It is up to you if you would like to bring any clothes, some parents prefer to just use a blanket.

## What if my baby is on regular medicine's at home?

If your baby usually takes prescribed medicine's at home, then please bring these with you when you get admitted to Ward 77, the day before the surgery. You will need to give the medicines to the ward who will lock them away to keep them safe, and they can ask for the Doctors to prescribe the medicines on your baby's prescription chart. The nursing staff will administer all regular medications whilst you are in the hospital, as parents are not allowed access to medication whilst their child is an in-patient.

If you, the parent or guardian, are on any medications, these will also need to be given to the nursing staff on admission so they can be appropriately stored and secured.

## Going in the pram

Two weeks after the surgery, your baby will usually be allowed to go in a pram, allowing you to take them for walks within the Hospital grounds. The Hospital are unable to provide a pram due to infection control, therefore we advise you bring a “carry cot” style pram if you would like the opportunity to take your baby for walks. It is important that it is a carry cot/bassinette pram as your baby will not be able to wear straps or a harness and must remain flat within the first 4 weeks after the surgery, so cannot go in an ordinary pram or pushchair. It is entirely your choice whether you wish to use a pram following the first two weeks, but families often appreciate the opportunity to get off the ward for short durations of time.

Due to the COVID-19 Pandemic, we are actively discouraging families from moving around the ward/Hospital to reduce the spread of infection. Therefore, you may not be able to utilise a pram whilst these restrictions remain in place.

## Pin Cares & Mermaid Bandage Changes

Two days after the surgery, we start performing daily pin cares and mermaid bandage changes. The two pin sites where the external fixator (metal frame) go into your baby’s pelvis are cleaned using some salty water to reduce the chance of infection. This can be uncomfortable at first for your baby but they quickly get used to it and the procedure becomes less painful as they begin to recover from the surgery. Initially, timing the pin cares with when baby is due pain relief can be helpful to make them as comfortable as possible.

We also change the mermaid bandages (the bandages around your baby’s legs) once a day from day two following the surgery. This is important as it gives us the opportunity to wash your baby and check for any red areas of skin which may become sore. Sometimes the bandages need to be changed more regularly if they get soiled with poo.

You will be offered the opportunity to learn how to carry out the pin cares and mermaid bandage changes yourself following the first few days. There is no pressure for you to do this, however some parents find it therapeutic to be able to provide this care for their baby whilst they are in the Hospital.

## What about when we are ready to go home?

You will usually be admitted to the Hospital for 4-6 weeks from the date of your baby’s surgery. Between week 3 and 4, we will take an x-ray of your baby’s pelvis to check the positioning of the bones. After 4 weeks, your baby is then usually ready to have the external fixator (metal frame) and the small thin tubes (stents) that have been draining all the urine (wee) away from the kidney’s removed. You will remain an in-patient in the Hospital for a few days after the fixator and stents have been removed.

This can be done either on the ward whilst your baby is awake, or sometimes we will take your baby back to theatre and they will have it done whilst they are asleep. The Doctors will make the decision in the weeks following surgery and will let you know if they are planning to take your baby back to theatre on the 4<sup>th</sup> Monday following the surgery.

Occasionally, a small thin tube (catheter) will be left in the urethra (the opening where wee comes out) for two weeks following removal of the stents, and you can usually go home with this tube draining into a nappy.

When the stents have been removed, your baby will be left with one tube in their tummy (supra-pubic catheter) whilst you learn to pass a small flexible tube in and out of the bladder twice a day (intermittent catheterisation). Once you have learnt to do this, and providing there are no problems, the supra-pubic catheter can be removed, and you can be discharged. Your intermittent catheters are then organised to be routinely delivered to you at home. If the Doctors decided to leave a catheter in the urethra for two weeks (as described above) then you will be given a separate date to come back to the hospital to have the catheter removed and learn how to intermittently catheterise your baby.

Your baby will need to continue to wear the mermaid bandages for 2 weeks from the date the frame was removed, as this helps to further stabilise the bones as they continue to heal. You will be provided two weeks-worth of bandages to take home with you and given the date on which to stop applying them at home.

## Contact

If you would like to discuss any of the information in this leaflet further or still have questions about coming into Hospital, please contact a member of the team.

In case of problems or advice please call:

Debra Collins (secretary)	(0161) 701 1636 (appointment queries)
Jenny Powell (Clinical Nurse Specialist)	(0161) 701 7707 (for clinical queries)
Ruth Hurrell (Clinical Psychologist)	(0161) 701 4514 (for psychology queries)
James Devine (Theatre Scheduler)	(0161) 701 0779 (for surgery date queries)
Ward 77 (urology ward)	(0161) 701 7700 (for urgent advice)
Ward 76 (day case)	(0161) 701 7600 (for urgent advice)

