

Bladder Exstrophy & Epispadias Transition

In healthcare, we use the word 'transition' to describe the process of preparing, planning and moving from children's to adult services.

Transition is a gradual process that gives you and everyone involved in your care time to get you ready to move to adult services and discuss your healthcare needs you will have as an adult.

Transition is about making plans with you and not about you.

We understand that moving away from a team of doctors and nurses that you have been with for many years can be scary but hopefully, by getting involved in the transition process, you will feel more confident and happier about the move.

Why do I have to move?

As you get older you will find that some of the things you want to discuss or some of the care you might need is not properly provided by our children's services.

Adult services are used to dealing with all sorts of issues that may arise as you go through adulthood.

You may also find that you would prefer to be seen in a more grown-up environment, rather than the usual children's departments or wards.

When do I have to start going to adult services?

This will be discussed when you come to the Bladder Exstrophy Transition Clinic. The Transition Clinics include both paediatric and adult staff. This means you can start getting to know these people for a long time before you move to adult services. We have put everyone's name and photo on the back of this newsletter so you can start getting to know them now. Moving to adult services is a slow and gradual process and will not happen overnight.

Your Bladder Exstrophy & Epispadias Transition Team



Mr David Keene
Consultant Paediatric



Mr Max Cervellione
Consultant Paediatric Urologist



Mr Ian Pearce
Consultant Adult



Dr Gail Busby
Consultant Gynaecologist



Dr Ruth Hurrell
Consultant Clinical Psychologist (Paediatric)



Lucy Ferguson
Assistant Psychologist (Paediatric)



Jenny Powell
Clinical Nurse Specialist (Paediatric Urology)

Who can I talk to about my condition?

At different times you may have different questions about your condition. It can help to talk to someone you trust to get some answers and think things through. Aside from your family and friends, the Bladder Exstrophy Transition team are around to help with any questions you might have. You can speak to the team at appointments or phone our Bladder Exstrophy transition nurse or psychologist in between times if you would like to see someone sooner.

How do I explain my condition to my friends?

Lots of people ask us for advice on the best way to tell their friends about Bladder Exstrophy and Epispadias. It's important to remember that there's no right or wrong way to tell people you trust and so you should do what feels right for you. Here are a few tips we have picked up along the way:

It helps to talk to people who you trust and who care about you

Think about what you might say before you have to say it. Try to say it out loud in private first to check you feel comfortable.

Many people find it best to explain a little bit about their condition, reassure their friends that they are okay and then change the subject. So, for example, if a friend asked, 'why do you have to go into hospital?' or 'who do you spend longer in the toilet than me?' You could say something like 'my bladder didn't grow enough when I was little, so I have to have some operations to fix it. It makes me need to wee more often and for longer.' Usually friends just want to be reassured that you are okay because they care about you. You can add something like 'I'm okay though so don't worry.'

If it is a close friend you might also want to say something like 'thanks for asking me how I am. I may want to talk to you about it again if that's okay.' You can then change the subject by talking about something else; 'so what are you doing this weekend?'

It is normal to feel unsure about talking to others and many people worry about what their friends might think. But often people tell us it really helped when they found a safe way to tell friends. If you would like to feel more confident about talking to others the Bladder Exstrophy Transition Nurse and Psychologist are here to help.

How can I deal with being bullied by other people?

Sometimes bullies make fun of people who a bit different from them, which can make the person feel upset or worried. Being bullied is something that no-one should have to put up with. If you are being bullied, you should try to tell an adult you trust; this might be a teacher or a member of your family. The Bladder Exstrophy Transition Nurse and Psychologist can also support you by helping you to learn some new skills so that you can cope with it. They can also help you family and the school to find a way to stop the bullying.

How does my condition affect my career choices?

Bladder Exstrophy or Epispadias should not stop you from doing the job you want to do. There may, however, be some careers that you will need to think about more carefully such as going into the Army. The Bladder Exstrophy Transition Team can refer you to a service which offers advice and support with careers, jobs and further education.

Is it going to be possible for me to have a relationship?

Most adults with Bladder Exstrophy/Epispadias are able to have good romantic relationships just like anybody else. However, it can be quite normal for people to worry about this. You may need some additional surgery or medical treatment to make this possible. Everyone is different so it is best to ask the doctors or nurses. You can ask them when you are on your own or when you are with your parents. You can also speak to the Bladder Exstrophy Transition Nurse or the Psychologist if you have any questions or are worried.

Will I be able to have children?

Many adults with Bladder Exstrophy or Epispadias go on to have children, but everyone is different so the best thing to do is ask the doctors or nurses about this at your next clinic appointment or by calling Jenny, the Bladder Exstrophy Transition nurse. You can ask when you're on your own or when you are with your parents.

What happens about ordering my catheters (if you use them)?

You are set up with a home delivery company. The company requests your catheters on a monthly basis via prescription from your GP. Once they get the prescription they will then send out your catheters. Never let your catheter supply run too low; if you notice you have less than one week supply left, ring your company and ask for more. Your nurse specialist and GP can help support you with any problems you may have.

Do I pay for prescriptions?

Because you have a condition which requires you to self-catheterise, you are exempt from prescription charges. However, once you are 19 (if in full time education) or 16 (not in full time education), you will need to apply for a medical exemption certificate from this website:

<https://www.nhsbsa.nhs.uk/exemption-certificates/medical-exemption-certificates>.

If you do not have an exemption certificate and are no longer classified as a child, you will need to pay per prescription.

I want to travel abroad, what do I need to do about my medical equipment/condition?

Your condition should not limit your ability to travel but there are some steps you can take to make things easier. Your nurse specialist can provide you with a "travel passport" or letter which states you need to travel with essential medical equipment and that this needs to be on your person at all times

(this avoids any issues at check in/security checks). Please ensure you have travel health insurance and that you inform the provider of your medical condition. Lastly, always keep essential medical equipment in your carry-on as, should your baggage go missing, you will still have everything you need with you.

Am I entitled to any Benefits?

You may be entitled to various benefits depending on your medical condition and circumstances. You can find more information on benefits and how to apply at this website:

<https://www.citizensadvice.org.uk/benefits/>.

If you require medical evidence, then please contact your adult Urology Nurse Specialist.

Who do I contact in an Emergency?

If you are seriously concerned about your health (e.g. you are struggling to catheterise) then you need to attend your nearest A&E department, in necessary by ambulance by calling 999, but be prepared that they may not be experienced in your condition so you may be transferred to Manchester for a full assessment. If you feel you are not seriously unwell then you can ring you GP and make an appointment or attend your nearest walk in centre. If you aren't sure, then you can dial 111 which is a 24 hour NHS helpline who can provide you with some advice.

What do I do if I can't/don't want to attend an appointment?

If you are unable to attend an appointment, please ring the appointments line number found on your appointment letter or your Urology Consultant's Secretary (see contact information). Your appointments are incredibly important in making sure you remain safe and healthy and efforts should always be made to attend or rearrange wherever possible.

This is only a start

This leaflet is designed to get you to start thinking about adult services and the transition process.

For every person the process will be slightly different. By talking about transition early, you should have plenty of time for discussions and questions, ensuring that you are fully prepared when the time comes to make the move to adult services.

You may like to use this section to jot down any of the questions you would like to ask about transition

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