Hypospadias for Adolescents

What is Hypospadias?

Hypospadias is a condition where the urethra (the hole you pass urine from) is not in the normal place. It can be anywhere from just off the glans (the tip of the penis) to between the scrotum. The further away the hole is from the normal place the more "severe" the hypospadias.

Why was I born with it?

Around 1 in 300 boys in Scotland are born with some degree of hypospadias so it is not rare. In some boys hypospadias is the result of a variation in a gene or chromosome (the rod-like structures within our cells that are the packages for our genes). In many centres, it is routine practice that boys with hypospadias, beyond the glans, will be offered genetic testing. You may be referred to Paediatric Endocrinology or Clinical Genetics to discuss these tests and the results. However, for many individuals the cause remains unclear.

How was it treated?

You will have had at least one (and perhaps several) operations to treat the condition. These may have been done when you were a baby and you have no memory of them or may have been when you were older in which case you may remember it/them well. More severe hypospadias tends to need more than one operation to treat it. Your parents may be able to give you some information but if you

want more then you or your parents can contact the hospital or surgeon who looked after you.

Are there likely to be any long term problems with passing urine?

If you can pass urine normally now then you should have few problems when older. If you have not completed puberty yet then things can occasionally get worse at that time. If you are having problems with passing urine just now it may be worth going back to see your surgeon for a check-up.

Am I a normal boy?

Yes, very much so. You can usually do what every other young man of your age can do. If you had a severe hypospadias or additional problems with the development of your genitalia, it is quite possible that as a young child you would have been seen by other specialists including doctors who are specialists in hormone tests and treatment. There may be a need to do this again around the time of puberty and you can discuss this with your doctors.

Will I be able to have sex normally?

Yes you can. Boys born with hypospadias usually have normal sized penises which after surgery are straight when erect. This means you will be able to masturbate or have sex like any other young man of your age. In some rare instances of severe hypospadias the

penis may be quite small and these boys may need some advice about having sex.

Will I be able to have children?

The answer again is yes. To make a child the "normal" way a boy needs to produce sperm - which needs at least one working testicle, get a straight erection - which was discussed above and be able to ejaculate the sperm out of his penis. If you can do all of these you have the potential to produce children. Again, in some rare instances this doesn't all work properly and you may need some medical assistance to be able to have children which is often successful.

How can I find out more about any surgery I have had?

Your parents may be able to give you some information and your GP can also be helpful. You can ask to speak to a surgeon who performs hypospadias surgery. This may be your own surgeon or someone else who works in the same department. You have the right if you wish to see your medical notes although it is probably better if it was explained to you by a surgeon.

Who can I speak to if I am unhappy or want some more advice?

Again your parents or GP would be a good place to start. There are also websites run for and by other people who have experience of hypospadias surgery. Visit the links page on

the SDSD website to find out more. Many units now have a psychologist who is part of the clinical team and they can be very useful people to talk to about your concerns.

I am embarrassed about how my penis looks. Can anything be done about it?

Depending upon the appearance and what has been done before it may be possible to improve it. The best person to discuss this with would be a surgeon who is experienced in hypospadias surgery and your GP will be able to find out who that is in your area. Any procedure is likely to involve an anaesthetic and an operation but your surgeon will be able to advise you on this.

Why have my parents not told me anything about my condition before?

Being born with hypospadias is nothing to be ashamed of but as it is a condition of the penis it tends to be kept quite private. Parents often feel they want to forget about the whole experience which would have been quite difficult for them when you were born and when you had surgery. They also are keen that you are not teased by people and are usually trying to protect you. Some parents also find it embarrassing talking to their children about things like penises and sex. Similarly if you don't feel comfortable talking in front of your parents you can see the doctor or surgeon on your own.

Who has reviewed SDSD activity?

NHS Quality Improvement Scotland (QIS) National Services Division, NHS Scotland (NSD) Director of Health Information & Technology, GGCHB

This information sheet was originally created in March 2005 by members of the Scottish Differences of Sex Development Network.

www.sdsd.scot.nhs.uk

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Or visit our website:- www.sdsd.scot.nhs.uk

This leaflet will be available in other languages (eg Punjabi, Urdu, Polish) or formats (eg larger print) on request from the SDSD office or visit the website www.sdsd.scot.nhs.uk



Patient Information Leaflet

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