

Differences in sex development (DSD) clinic

Information for children, families and carers

We've given you this factsheet because your child has been referred to our differences in sex development (DSD) clinic. It explains what the DSD clinic is, why your child has been referred to the clinic and what to expect at your child's first appointment. We hope it helps to answer some of the questions you may have. If you have any further questions or concerns, please contact us using the details at the end of this factsheet.

What does the term 'differences in sex development' mean?

Differences in sex development (DSD) is a term used to describe a broad group of rare conditions involving genes, hormones and reproductive organs, including the genitals. It means a person's sex development is different than expected.

A DSD may be diagnosed shortly after your baby is born, or it may not be discovered until much later when your child reaches puberty (when a child's body begins to develop and change as they become an adult). It is typical for puberty to begin at any point between the ages of 8 and 13 in girls and 9 and 14 in boys.

There are many types of DSD, including:

- a child may be born with sex chromosomes usually associated with being female (two X sex chromosomes) but have reproductive organs and genitals that may look different from most girls
- a child may be born with sex chromosomes usually associated with being male (one X and one Y sex chromosome) but have reproductive organs and genitals that may look different from most boys
- a child may be born with both ovarian and testicular tissue
- a child may be born with the expected genitals but have a different sex development
- a female child may be born with the expected external genitals but no womb

What is the DSD clinic?

The DSD clinic is a specialist clinic made up of a wide range of healthcare professionals, all with expertise in DSD. The aim of the clinic is to provide information and support to those affected by a suspected or definitive diagnosis of DSD.

We recognise that each family coming to the DSD clinic may be at a different stage in their journey, from having initial investigations and receiving a definitive diagnosis to exploring treatment options and planning for the future. What we discuss at your child's appointment at the DSD clinic will vary, depending on what stage of the journey your child is at.

We run the DSD clinic three times a year at Southampton Children's Hospital. The clinic offers a multidisciplinary approach, providing you and your child with the opportunity to meet with lots of different medical specialties at one time, reducing your number of hospital visits.

You and your child may come to the DSD clinic once and not need to visit again, or you may be invited back to the clinic in the future if your child needs further investigations or treatment.

Why has my child been referred to the DSD clinic?

Your child's doctor may have referred your child to the DSD clinic for further investigations if they were concerned about your child's:

- genital development
- progress through puberty

or if a recent scan or test has shown that your child has any physical or hormonal differences.

Coming to the clinic does not mean we are giving your child a definitive diagnosis of a DSD condition. Instead, it provides you with the opportunity to discuss the different tests and investigations your child could have to help us better understand their current needs and create an individual care plan for them while they await a diagnosis. The clinic is also a good opportunity for you to ask any questions you may have. We understand that waiting for a diagnosis can be a difficult time for both you and your child, so please contact us if you have any questions or concerns. We are here to support you both.

What will happen at the clinic?

During your child's appointment at the clinic, you will be seen by lots of different healthcare professionals. You may be seen by a few at the same time, or you may be seen by them separately over the course of the morning. If you feel there are too many people in the room with you at any time, please let us know.

We may ask to examine your child. If you and your child are happy for us to do this, we will offer them a chaperone (another member of staff who can be present during the examination). If they do not wish to be examined, that is completely fine. We will only perform examinations when clinically necessary.

If you would like to speak to any members of our team in private, please ask us and we can arrange a suitable time and place.

Who will my child be seen by at the clinic?

The DSD team is made up of lots of different healthcare professionals, from different medical specialities, including:

- an endocrinologist (a doctor who diagnoses and treats hormone-related problems and complications)
- a urologist (a doctor who tests, diagnoses, treats and manages conditions relating to the bladder, kidneys, urinary tract, genitals and reproductive system)
- a clinical geneticist (a doctor who diagnoses and looks after families with genetic disorders)

- a psychologist (a trained mental health professional who provides emotional wellbeing support)
- a gynaecologist (a doctor who specialises in female reproductive health)
- an endocrine nurse specialist (a nurse who specialises in the care of children with hormone-related problems and complications)

Who you meet at the clinic will depend on your child's diagnosis and/or the stage of their sex development. You may only meet some of these healthcare professionals once, or you may meet them multiple times as your child gets older.

What makes the DSD clinic specialist?

Before your child's clinic appointment, the whole DSD team (up to 25 different healthcare professionals) will meet to discuss your child's case. This means that lots of experienced healthcare professionals will have thought carefully about and agreed on what is best for your child and what support will be most useful for you and your family.

This pre-clinic meeting also allows us to check the most up to date information and research surrounding your child's specific variation in sex development, which will help us to agree on the best way to care for your child.

What will happen after my child's appointment at the DSD clinic?

We will send you a letter in the post that summarises the discussions and plans that we made during your child's appointment. We know that these appointments can be very tiring and sometimes worrying for parents and guardians. Tiredness and anxiety can make it difficult for people to process information, especially clinical information. If you are struggling to remember what we discussed during your child's appointment, or you would like another chance to review the information, please do let us know. We will be very happy to answer any questions or discuss any concerns you may have.

Making decisions about your child's treatment

While we will discuss your child's case ahead of your child's clinic appointment, we understand that you as parents or guardians know your child best, so we will never make any decisions regarding their care or treatment without discussing it with you first.

Before we make any decisions about your child's treatment, we will discuss this with you multiple times, to allow you time to think about what is best for your child. If you have any questions or concerns about anything, please ask us. We will always be happy to talk through anything we have discussed again. It is important that you understand the implications of the choices we make before we make them.

Your feedback

We may also send you a link to some questionnaires about our service. We would be grateful if you could complete these. Your feedback will help us to understand what your experience of coming to the DSD clinic was like, which will help us to continue to improve our service.

Research

We may also offer you the opportunity to participate in research studies, but you are under no obligation to do this. If you would like more information about our on-going research studies, please let us know and we can discuss these with you in more detail.

Contact us

If you have any questions or concerns, please contact us.

DSD clinic

Telephone: **023 8120 8719** (Monday to Friday, 9am to 5pm)

Email: pens@uhs.nhs.uk

If we are unable to answer your call, please leave a voicemail with your name, phone number and a short message, and a member of our team will get back to you within three working days.

Useful links

www.dsdfamilies.org

www.bsped.org.uk

www.nhs.uk/conditions/differences-in-sex-development

If you are a patient at one of our hospitals and need this document translated, or in another format such as easy read, large print, Braille or audio, please telephone 0800 484 0135 or email patientsupporthub@uhs.nhs.uk

For help preparing for your visit, arranging an interpreter or accessing the hospital, please visit www.uhs.nhs.uk/additionalsupport

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