- http://www.mrkh.org.uk/
  Specific information and support for Mayer Rokitansky Kuster Hauser (MRKH) syndrome.

- http://tss.org.uk/
  Turner Syndrome Support Society.

- http://www.hypospadiasuk.co.uk/
  Information about hypospadias for men, boys and parents from the UK Hypospadias Trust.

Other formats:

If you would like this information in another language or audio, please contact Interpreting services on telephone: 01223 348043, or email: interpreting@addenbrookes.nhs.uk
For Large Print information please contact the patient information team: patient.information@addenbrookes.nhs.uk

We are a smoke-free site: smoking will not be allowed anywhere on the hospital site.
For advice and support in quitting, contact your GP or the free NHS stop smoking helpline on 0800 169 0 169.

Weston Centre
Addenbrooke’s Treatment Centre

Patient Information

Welcome to the Children and Young People’s DSD Clinic
Information for Parents and carers

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Authors: Clinical Psychologist
Pharmacist: N/A
Department: Cambridge University Hospitals NHS Foundation Trust, Hills Road, Cambridge, CB2 0QQ
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What is the DSD Clinic?

DSD stands for Disorders of Sex Development. These are conditions that affect how your child develops as a boy or girl.

DSD is a term that not everyone feels comfortable with, but it is the best fit for the wide range of conditions that are seen in this clinic.

Not everyone agrees that these differences should be thought of as ‘disorders’. Some people prefer DSD to stand for Different or Diverse Sex Development, as these are variations of sex anatomy that occur naturally and are not necessarily medical problems.

While it is ‘just a name’, the words that we use are important as they affect how we understand and adapt to these differences.

Who will I meet?

The DSD clinic is a multidisciplinary (MDT) clinic. This means that there are many different health care professionals from a range of specialties involved. Not everyone will need to see all members of the team. A pre-clinic meeting is held prior to the clinic to make sure you see the correct people.

What if I have questions after the appointment?

Please do feel free to contact our team if you would like to discuss any points from the appointment or just have a general question.

To direct you to the correct member of the team, please contact:
Endocrine nurse specialists for any hormone or medication questions – Sam, Karis, Susan and Betty: (01223) 217496
Surgical nurses for any surgery questions: (01223) 586973
Psychologist – Louise Martin: on 07929 336884
Paediatric endocrine clinic reception: (01223) 348576

What if I can’t make an appointment?

Please let us know if you cannot make an appointment by calling reception on: 01223 348576 at the earliest possible opportunity.

Resources

  An information and support resource for families with children, teens and young adults who have a DSD.

- [https://www.med.umich.edu/yourchild/topics/dsd.htm#info](https://www.med.umich.edu/yourchild/topics/dsd.htm#info)  
  Information and support about DSD.

- [http://www.aissg.org/](http://www.aissg.org/)  
  Androgen Insensitivity Syndrome Support groups.

- [http://www.dsdtens.org/](http://www.dsdtens.org/)  
  DSD information and support for teens.

- [http://www.livingwithcah.com/](http://www.livingwithcah.com/)  
  The Congenital Adrenal Hyperplasia Support Group.
What if my child needs a blood test?
Blood tests can be done here in clinic with one of our nurses. We can use “magic cream” or “cold spray” to help numb the area if your child is worried about it hurting. Please come and speak to a member of the team if you have any questions.

What if my child needs an x-ray?
X-rays are taken in the x-ray department. This can be found on Level 3 of the Addenbrooke’s Treatment Centre.

What if my child needs surgery?
If your child needs surgery, the paediatric surgical team will be in touch with you with a date.

What if my child needs to be examined?
The doctor may need to examine your child; this may include examination of their genitals. It is hospital policy that another member of staff is present for this. This person is called a ‘chaperone’ and will be asked to observe the examination.

Please tell us if you or your child feels uncomfortable with examination, then we can talk with you about why and whether it is necessary. You have the right to ask that only the doctor and chaperone are present for the examination; other team members do not need to be in the room while this is done.

You or your child has the right to refuse examination. The doctor will explain how this will affect the consultation.

What do all the different people do?
Endocrine doctors
This is a doctor who looks after people’s hormones. Hormones are chemical messages which go around the body to control growth and development.

Surgeons
The surgeon on our team is a urologist. They are experts in surgery of the urinary tract and reproductive organs of boys and girls.

Gynaecologist
The gynaecologist looks after girls’ fertility, reproductive system and also performs surgery. They can also advise on the future fertility of both boys and girls.

Psychologist
The psychologist is here for you or your child to talk to about any aspect of the medical condition or treatment that would be helpful. For example, some families find it helpful to talk during or after diagnosis, when considering surgery, or before talking to their child about their condition.

Geneticist
Geneticists are experts in the building blocks called genes and chromosomes that make a person who they are. Looking at these building blocks can sometimes help to explain medical conditions.

Endocrine nurse specialists
These nurses work alongside the endocrine doctors. They are involved in weighing and measuring, teaching and taking blood tests for hormones.

Surgical nurse specialists
These nurses work alongside the surgeon. If your child is admitted for surgery, they provide teaching and after care advice.
What happens at the appointment?

**Telephone call**
Before the appointment, we will try to contact you by phone to discuss the appointment and any questions you may have. With your permission, we will feed this back to the team during the pre-clinic meeting to try and provide the best care for you and your child on the day.

**Arrival**
When you arrive you will need to check in at reception. Our receptionist may check details such as your address and phone number.

**Endocrine nurse specialists**
The nurses will weigh and measure your child and ask about any medication they are on. If you are new to clinic, they will also measure parents' heights.

**Seeing the team**
Your child will then be seen by members of the team. This may be in one longer consultation or in several smaller ones.

**Investigations**
If your child needs blood tests or x-rays, these can be done before you leave.

**Departure**

How long will the appointment take?
Seeing several different members of the team and having investigations does take time. We will try to see you and your child as swiftly as we can but please be prepared to be at the hospital for most of the afternoon.

How often do we need to attend the clinic?
Patients often “dip in and out” of the clinic according to their medical/surgical needs at the time. Some may be seen every year, others not for several years. In between appointments, you may be seen in the general endocrine clinic either here or at your local hospital. Your doctor will discuss this with you.

Does my child have to come to the appointment?
We like to see your child at the appointment to assess how they are growing, possibly examine them and carry out any investigations which may be needed. If you would rather they were not present for some parts of the consultation, please let us know and we can arrange to see you without your child present.

How do we get a copy of the clinic letter?
You should automatically be sent a copy of the letter from your child’s appointment. If it does not arrive, please contact our secretary on (01223) 274311 for a replacement.

How do we get the results of any investigations?
Where possible, the results of any investigations will be included in the clinic letter. Some tests take several weeks for a result.