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Overview of health surveillance schedule for children with Down Syndrome local to Darent Valley Hospital
For parents and carers

Children with Down Syndrome are generally fit and healthy. However, children with Down Syndrome have a higher risk of having some health conditions.
These conditions include heart disorders, bowel abnormalities, digestive problems, hearing and vision impairments, thyroid dysfunctions and blood disorders.
For this reason, children with Down Syndrome need to have extra health checks during their childhood to make sure these conditions are picked up early and treated properly. This table gives an overview of the health checks that your child with Down Syndrome should have.
Your child may need additional checks if they have a particular health condition.

	Birth – 1 year old	Aged 1-2 years old	Preschool checks	School age
Community paediatrics review	Every child with Down Syndrome is seen during their childhood by the community paediatric team at Gravesham Community Hospital/Darent Valley Hospital. At each review, any concerns will be discussed, your child will be examined, have their development assessed, and be checked for the common problems that children with Down Syndrome can have. They will be reviewed every 6 months until they are 4 years old, then every 1 year until they are 18 years old.			
Hearing checks	Your child will have their hearing checked soon after they are born, before you leave hospital.	Your child will then have their hearing checked by an audiologist at Gravesham Community Hospital when they are around 8 -10 months old.	Your child will then have 6 monthly hearing checks till the age of 2 years and to continue annually through school age years.	
Eye checks	Your child will have their eyes checked in their newborn routine check. This is done within the first 72 hours after they are born. It is usually done by a paediatric doctor. They are checked again at 6-8 weeks by the GP.	Your child will have their eyes checked when they are 18-24 months old by an ophthalmologist/Eye doctor at Queen Mary's Hospital.	Your child will have their eyes checked again when they are 4 years old by an ophthalmologist at Queen Mary's Hospital.	Your child will then have their eyes, and vision checked every 2 years.
Heart checks	Your child will have their heart checked before they leave hospital by a paediatric doctor. If any concerns are picked up at this stage, your child with have a heart scan performed by a cardiology doctor before they are 2 weeks old. If no concerns are picked up before leaving hospital, they will have a heart scan performed by a cardiology doctor before they are 6 weeks old. The heart scans may be done at your local hospital, or at Evelina Children's Hospital.	At each community paediatric appointment, the doctor will check for any symptoms that could suggest a heart problem. If there are concerns at any age, your child will be referred for further tests by a cardiologist. If your child has a heart condition, they will be seen more regularly by the cardiology team at Evelina Children's Hospital.		
Growth monitoring	Your child will have their height and weight checked at every review with the Community Paediatric team (and head circumference for the first 2 years and subsequently if clinically indicated). Children with Down Syndrome have their own growth charts.			
Blood checks	Before you leave hospital, your child will have a blood test to check for any serious blood disorders. They will also have the Newborn heel prick test done on day 5, which checks for thyroid problems and other rare conditions. Your child will have their thyroid function checked again when they are 4-6 months old.	Your child will have their thyroid function checked every year with a blood test. Other blood tests will be performed if there any concerns about your child's health. Lifelong annual screening is required for thyroid disorders.		
Vaccinations	Your child should receive all the normal vaccinations during childhood. If they have particular problems, such as breathing problems, they may be advised to have additional vaccinations.			
Other checks	Your child may be seen by other specialist teams. For example, the occupational therapy, speech therapy, neurology, endocrinology, gastroenterology, respiratory or haematology team			

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Antenatal care

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When you refer for antenatal care, the Midwife should discuss the screening test offered for Down's, Edward's and Patau's syndrome. This discussion should take place as early as possible, ideally before 10 weeks of pregnancy.

On the day of your 12 week scan, the sonographer should confirm if you consent to screening for Down's, Edward's and Patau's screening. If you agree to test, the sonographer will measure a pouch of fluid on the back of baby's neck called the Nuchal Translucency.

After your scan, you will be directed to have a blood test taken. It is important the scan and blood test take place on the same day to ensure it is accurate.

The blood sample is sent to a specialist laboratory. A result is generated which identifies if you have a higher or lower chance of a baby born with Down's, Edward's or Patau's syndrome. If the result is lower chance you will receive a letter routinely in the post to your home address.

If your result returns as higher chance, a specialist midwife will contact you to offer further testing options. These tests include Non-Invasive Prenatal Testing (NIPT) or Prenatal diagnosis (PND) in the form of a Chorionic villus sampling (CVS) or amniocentesis.

If your baby is confirmed to have Down's syndrome you will be supported by the specialist midwifery team. Other specialists will also support you in the antenatal period dependent on any other anomalies are detected on scan.

You should be signposted to support groups in the antenatal period to better understand Down's syndrome.

The place and timing of your baby's birth will depend on how the baby is growing and if there are any other concerns in the pregnancy. Sometimes it is safer for the baby to deliver at a specialist hospital if the baby requires support, for example a heart defect.

It is very likely that your baby will be taken to the Special Care Baby Unit (SCBU) after birth. The length of stay in the unit will depend on how much support the baby needs, e.g. feeding, keeping warm

Timing of Screening

Combined screening for Down's, Edward's and Patau's syndrome can be completed between 11+2-14+1 weeks of pregnancy. Quadruple testing for Down's syndrome can be completed between14+2-20+0 weeks of pregnancy

Screening Test

It is important to remember a screening test does not diagnose health conditions. There is a small chance the screening test can be wrong, and the baby is born with/without a health condition.

Health professionals

If your baby is suspected to have other abnormalities, the relevant team will support you in the antenatal period. This may involve the neurological team, cardiac team or surgical team.

From birth

Before your baby is born, you might already know that they have Down Syndrome. This usually happens if the screening tests picks up certain features which lead to a definitive test being done to confirm whether your child has Down Syndrome. There are two ‘definitive’ tests that are used – an ‘amniocentesis’ or ‘CVS’. These are types of genetic test.

Sometimes, you might be told that your child may have Down Syndrome after they have been born. This happens because the screening test doesn’t pick up every child that has Down Syndrome. If may also happen if you chose not to have a screening test done during the pregnancy. If you child has some ‘clinical features’ of Down Syndrome, they will be seen by a senior paediatric doctor. This doctor will review your child and take a blood test from them. This blood test will look at your child's chromosomes and will confirm whether your child has Down Syndrome. The result of this test takes about 48 hours.

If you child has Down Syndrome, they need to have some additional checks done before they leave hospital. These checks are done to pick up common problems that children with Down Syndrome can have. These checks will involve the following:

1. A blood test. This is to check for any serious blood conditions, including types of blood cancer. These blood conditions are uncommon, but it is important to test for them.
2. Oxygen saturation check and ECG (Electrocardiogram). These checks are to help pick up any serious heart problems and further assessment is planned, as necessary.
3. Newborn hearing check. This check is done for all babies before they leave hospital. Children with Down Syndrome can have problems with their hearing, so it is important that this test is done.

Before your child is discharged from hospital, the medical team will make sure that:

- Your baby has passed their first poo (meconium). Not passing meconium could be a sign of a problem with their digestive tract, such as Hirschsprung's disease.
- Your baby is feeding well.
- Your baby has been referred to the health visitor team, to make sure you and your family have all the support you need when you are discharged home with your new baby.
- Your baby has hearing check as the newborn hearing check before discharge.

When you are discharged from hospital, the medical team will also refer your child to the Community Paediatrics team. There is a specific team within the Community Paediatrics team that look after children with Down Syndrome, as well as other children with complex needs. This is called the ‘CDCS team’. The Community Paediatrics team will help to look after your child throughout their childhood.

Clinical features of Down Syndrome

Facial features such as upward slanting of the eyes, a protruding tongue, or a flat nasal bridge.

Hand features, such as short fingers, incurved little fingers or a single palmar crease.

Reduced muscle tone (floppiness).

What is CDCS

It stands for Child Development Coordination Service. It is a Multiagency, Multidisciplinary service to coordinate the care of pre-school aged children with complex health and educational needs.

Feeding support

Children with Down Syndrome can often breast feed effectively, if that is how you choose to feed you baby. You may require some additional support with breastfeeding, which can be provided by some specialist midwives on the Postnatal Ward, or by the community midwives or health visitors.

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0 – 6 months

Community paediatrics

Every child with Down Syndrome is seen by the community paediatric team at Gravesham Community Hospital. Your child will be referred to a specific team within this service – the CDCS team. This team will first see your child when they are around 3-6 months old. At this appointment they will:

- Monitor your child's development.
- Plot your child's growth in their electronic records and red book.
- Check for common problems that children with Down Syndrome can have.
- Make sure that your child is being looked after by all the right medical teams.
- Make a referral to Audiology for a Hearing assessment.

Eye checks

Your child's eyes will be checked for any obvious physical problems as part of the newborn physical examination.
Your child's eyes will be checked again when they are 6-8 weeks old by their GP.
Those who start to squint or show abnormalities of gaze, visual behaviour or attention, should be referred to ophthalmologist.

Speech and language therapy (SALT)

Most Babies with Down Syndrome can successfully breast fed. If the Baby is feeding well, they do not need SALT input. If there is feeding difficulties, within the first few weeks of your child being born the SALT team will contact you and offer an initial appointment via phone or in person to screen for any feeding difficulties.

Heart checks

Your child will have their heart checked before they leave hospital by a paediatric doctor. If any concerns are picked up at this stage, your child with have a heart scan performed by a cardiology doctor before they are 2 weeks old. If no concerns are picked up before leaving hospital, they will have a heart scan performed by a cardiology doctor before they are 6 weeks old. The heart scans may be done at your local hospital, or at Evelina Children's Hospital.

Blood checks

Before you leave hospital, your child will have a blood test to check for any serious blood disorders. They will also have the Newborn heel prick test done on day 5, which checks for thyroid problems. Your child will also have their thyroid function checked when they are 4-6 months old. If any problems are picked up with your child's thyroid function, they will be referred to the endocrinology team at their local hospital.

Vaccinations

It is very important that your child receives all the normal vaccinations during childhood. They should have vaccinations done when they are 8 weeks old, 12 weeks old and 16 weeks.

Problems to look out for

If your child has any of these problems, you should mention them to your health visitor or community paediatrician

Symptoms of **Gastro-Oesophageal Reflux Disease (GORD)** such as bringing up milk or being sick during or shortly after feeding, coughing or hiccupping when feeding or being unsettled during feeding.

Feeding difficulties, such as difficulty with sucking and swallowing, or with sleepiness during feeds.

Constipation or infrequent bowel opening. This could be a sign of a condition called Hirschsprung's disease.

What is CDCS

It stands for Child Development Coordination Service. It is a Multiagency, Multidisciplinary service to coordinate and plan the care of pre-school aged children with complex additional health and educational needs within Bexley Borough.

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6 months – 1 year

Community paediatrics

Your child will be seen by a paediatrician at Acorns when they are approximately 1 year old. At this appointment they will:

- Monitor your child's development.
- Plot your child's growth, including their length, weight and head circumference on the Down syndrome chart and the red book.
- Examine your child and check for common problems that children with Down Syndrome can have.
- Enquire about uneven breathing during sleep and poor quality sleep. Sleep study is required if concerns arise.
- Make sure that your child is being looked after by all the right medical teams.
- Make sure that your child and your whole family are receiving the right support.

Eye checks

Those who start to squint or show abnormalities of gaze, visual behaviour or attention, should be referred to ophthalmologist.

Hearing checks

Your child will have their hearing checked by an audiologist at Gravesham Community Hospital when they are 8-10 months old . They will be referred by your child's Paediatrician.

Speech and language therapy (SALT)

Your child will have ongoing access to the monthly SALT group to help develop their communication and eating and drinking skills.

Your child will have 6 monthly communication reviews throughout the early years.

Heart checks

At each community paediatric appointment, the doctor will check for any symptoms that could suggest a heart problem. If there are concerns at any age, your child will be referred for further tests by a cardiologist.

If your child has a heart condition, they will be seen more regularly by the cardiology team at Evelina Children's Hospital or at your local hospital.

Vaccinations

Your child's next routine vaccination will be given when they are approximately 1 year old. If your child has any particular problem, such as breathing problems, they may be advised to have additional vaccinations. Children with Down Syndrome should also have an annual influenza and Covid vaccine. Household members should also consider having an annual influenza and Covid vaccine.

Problems to look out for

If your child has any of these problems, you should mention them to your health visitor or community paediatrician

Symptoms of **obstructive sleep apnoea**, such as restless sleep, loud snoring, or mouth breathing when asleep.

Any problems with **hearing or vision**.

Gastrointestinal problems such as constipation, tummy distension or infrequent bowel opening.

Delayed motor skills such as not sitting without support by 12 months old.

Symptoms of **infantile spasms**, such as sudden head dropping, or exaggerated startle reflex.

What is a Section 23 notification

Health professionals have a legal duty to notify the council of any concerns (known as a 'Section 23' notification) so that services can work together to ensure that a child's needs are not missed and that the right support is in place in good time (for example, when they start school).

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Pre-school (1 year – 5 years)

Community paediatrics

Your child will be seen yearly by the Community Paediatrician at this stage. Any concerns you have about your child's health and their development should be raised at these appointments. At the yearly appointments they will have their height, weight and head circumference checked and plotted. The paediatrician will check for common problems and address any concerns. At each review, enquire about uneven breathing during sleep and poor quality sleep. The paediatrician will check about any addition support that your child and your family might need, such as Disability Living Allowance.

Hearing checks

Your child will have 6 monthly hearing checks till 2 years and then annually, done by an Audiologist at Gravesham Community Hospital.

Speech and language therapy (SALT)

Once your child is in nursery or school, communication support will be offered within the educational setting.
Your child will have 6 monthly communication reviews throughout the early years.

Eye checks

Your child will be referred to Ophthalmology at the first follow up at 8weeks. Your child will have their eyes checked when they are 18-24 months old by an ophthalmologist/orthoptist at Queen Mary's Hospital. Your child will then have their eyes checked again when they are 4 years old by an ophthalmologist at Queen Mary's Hospital.

Vaccinations

Your child's next routine vaccination will be given when they are approximately 3 years 4 months old. Children with Down Syndrome should also have an annual influenza and Covid vaccine.

Blood checks

Your child will have thyroid function checked at 12 months with a blood test (T4, TSH, TPO antibody) and annually thereafter. They may be indicated sooner if your child develops symptoms of thyroid dysfunction.
Other blood tests will be performed if there any concerns about your child's health, such as about Coeliacs disease or problems with the immune system.

Other teams

Your child may be referred to other medical teams if needed.

Problems to look out for

If your child has any of these problems, mention them to your health visitor or community paediatrician

Symptoms of **cervical spine instability**, such as neck pain or pain behind the ear, restricted neck movements, change in walking (gait) or change in bowel/bladder control.

Symptoms of **Coeliac disease**, such as diarrhoea or new onset constipation, abdominal distension, faltering growth or a rash.

Symptoms of **thyroid disease** are nonspecific, hence the need for routine blood tests. Some features may be rapid weight gain, lethargy, mental health/ behaviour issues, dry skin, constipation.

Delayed motor skills such as not weight baring by 16 months or not walking by 30 months.

Problems with infections, such as very frequent infections or prolonged infections.

Other teams

If your child has not met their 'motor milestones' such as walking, they may be referred to the **physiotherapy team**.

School (5 years onwards)

Community paediatrics

Your child will continue to be seen yearly by a Paediatrician. Their growth and development will be assessed, and any new or ongoing problems will be reviewed. The paediatrician will check for common problems and address any concerns. At each review, enquire about uneven breathing during sleep and poor quality sleep.

Hearing checks

Your child will have their hearing checked by an audiologist at Gravesham Community Hospital, annually.

Blood checks

Your child will have their thyroid function (T4, TSH, TPO antibody) checked every year. If any problems are picked up with your child's thyroid function, they will be referred to the Endocrinology team at their local hospital.

Eye checks

After 4 years, your child will have their eyes checked every 2 years by an ophthalmologist at Queen Mary's Hospital.

Vaccinations

Children with Down Syndrome should have an annual influenza and Covid vaccine.

Other teams

Your child may have additional appointment with other health professionals, depending on what medical issues they have.

Problems to look out for

If your child has any of these problems, you should mention them to your health visitor or community paediatrician

Symptoms of **Coeliac disease**, such as diarrhoea or new onset constipation, abdominal distension, faltering growth or a rash.

Problems with infections, such as very frequent infections or prolonged infections.

Symptoms of **cervical spine instability**, such as neck pain or pain behind the ear, restricted neck movements, change in walking (gait) or change in bowel/bladder control.

Difficulties with **dental care** such as gum or tooth infection. Children with Down Syndrome may benefit from seeing a dentist with special training. They should see a dentist every 6 months.

Symptoms of **diabetes**, such as increased thirst, passing urine more often, extreme tiredness or weight loss.