

What support is available for children with Down Syndrome in **Stockton and Hartlepool**?

Before birth

- Pregnant mothers are offered antenatal screening (hospital)
- High chance counselling is available when requested (hospital)



- Support and Facebook groups are available through local (Down's Syndrome North East - DSNE) and national (Positive About Down Syndrome - PADS) charities and local Parent Carer Forums (PCF). Details are included in your new parent pack and gift box from the hospital

Birth to three years

- Regular medical and development checks take place. These will be through your community paediatrician and your midwife and then your health visitor is available for advice and support in between
- Ear, Nose and Throat (ENT) clinics are available. These can be referred to by a professional connected to your care (i.e. community paediatrician or health visitor) as and when necessary (dependent on need)
- Ongoing support from DSNE/Local Parent Carer Forum/PADS
- Dependent on need, your child could get support to access education. The provider/school can request additional funding
- Children requiring specific help with sitting, gross motor skills, eating, communication and early dressing skills can be referred to an occupational therapist (OT), physiotherapist (physio) or speech and language therapist (SALT) as required. The therapies work together as an integrated service (OT, physio, SALT (hospital))
- Information and advice on housing and any necessary adaptations can be accessed through your local children or family hub. There will be links to your Local Authority Early Help and Occupational Therapy Team



At birth

- A diagnosis is made by hospital staff, who have initial discussions with parents (hospital)
- Possible medical needs are assessed, and other professionals might become involved, including surgeons, cardiologists and dietitians (hospital)
- You can be linked with a Parent Champion for support through our local charity Down's Syndrome North East (DSNE). The details for contact can be found in your gift box or new parent pack received from the hospital at diagnosis
- A pre-discharge meeting will take place on the postnatal/neonatal ward and your health visitor will be invited to attend (Hospital/HDDFT/0-19 Service)
- Information about support, benefits and other services can be found through (DSNE/Parent Champions/PADS)
- Information about your new baby will be sent post-natally to your GP and health visitor
- Any referrals to specialist services will be made post-natally (dependent on need)



Three to five years 4

- Access to all appropriate departments and consultancy as appropriate to the child's specific needs (hospital)
- Yearly review with local community paediatrician from 36 months onwards (hospital)
- Ongoing support from DSNE/Local Parent Carer Forum/PADS
- Support in school is available to access the curriculum and develop learning and social skills. The school Special Educational Needs Coordinator (SENCO) job profile will assess and make recommendations based on need
- Support is offered at home and setting through advice and strategies to support the child's development and at times of increased needs, such as transition to school. Also training, for example signing (SALT, OT, physio and Early Years SENCO)
- Based on assessed needs, a SALT, physio and an OT can provide training for staff in school and parents (SALT, physio and OT)



Five to eleven years 5

- Access to all appropriate departments and consultancy (hospital)
- Community consultant paediatrician conducts yearly review (hospital)
- Ongoing support from DSNE/Local Parent Carer Forum/PADS
- Based on the assessed needs, support in school maybe available to access the curriculum and support at reviews and transitions (SENCO)
- Support with school transitions from professionals involved (SENCO and hospital)
- If child attends a mainstream or special school advice is available from a SALT, or a referral can be made depending on need. Where appropriate, support offered may include group or one-to-one input (SALT)
- Children attending mainstream or special school can be seen by a physiotherapist if there are concerns regarding gross motor skills or access to PE curriculum (physio)
- If your child attends a mainstream or a special school, OT support is available - depending on assessed need - including groups and one-to-one (OT). Social services provide OT home support



Secondary school (age 11–18 years) 6

- Ongoing support from DSNE/Local Parent Carer Forum/PADS
- Based on assessed needs, support in school to access the curriculum and support regarding learning and social skills maybe available (SENCO)
- The transitions co-ordinator in your local trust will support from age 14, Community Paediatrician will refer to help prepare for transition into adulthood/adult services (hospital)



- Based on assessed needs, an SALT, a physio and an OT can provide training for staff and parents and input to support the young person within their school if a specific need is identified (SALT, physio and OT)