

## For children 0-5 who have Down's syndrome and their families

If your child has been born with Down's syndrome, whether you know before or after birth, there are support services that all children and their families will be offered in Cambridgeshire. Not every child with Down's syndrome will require all of the services and not every child will need each service at the same time however your health visitor and Early Support coordinator will be able to assist you in organising support for your child and in turn support your family on this journey.

### Coming out of hospital after your baby is born

Your **Health Visitor** will provide information and a **referral to Early Support**.

**Medical care** for mother and child will be provided as it would for any new addition to a family, to get you home safely and begin your life together.

#### Early Support Coordinators

Your Early Support coordinator will help to coordinate information, referrals, services and support for your child and family. They also support the professionals working as a team around your child and family and can be contacted by you if your lead professional is not available.

**W:** [www.cambridgeshire.gov.uk/early-support](http://www.cambridgeshire.gov.uk/early-support)

**T:** 01223 884491 (Cambridge & South Cambs)

**T:** 01480 418646 (Huntingdonshire)

**T:** 01945 488048 (East Cambs & Fenland)

# Local Offer



## Early years support and checks

### Medical Care

After your baby is discharged from hospital they will be seen by a Paediatrician. An initial appointment, usually when your baby is 3-4 months old, will introduce the ongoing medical and developmental follow up. Many children require very little intervention and will only need monitoring, however some children will need more and the Paediatrician will discuss this with you.

**Cardiology check up;** as children with Down's syndrome are known to be more likely to have heart conditions, a heart scan is performed in the first days of life to ensure any concerns can be monitored.

**Eye check up;** you will be asked to attend an eye clinic to ensure there are no concerns with your child's sight that may impact on development. This appointment is normally when your baby is between 2-4 months old.

**Hearing test;** your child will have the new born test and then a second check at 8 months old to ensure there are no concerns with hearing that may affect development at a later time. Hearing tests will take place as required but at least once a year as some children are prone to glue ear and congestion.



### Early Support

Support will be tailored following assessment to meet your child's individual needs and is available if required from:

**SEND(Special Educational Needs and/or Disabilities) Specialist Services;** a multi-disciplinary team which includes specialist teachers, specialist practitioners and educational psychologists. If needed they can help you plan activities and ways to help your child learn in small achievable steps. This may be at a 'specialist group' at a Children's Centre or similar venue or at your child's setting/school.

**Speech & Language Therapy;** if required provide support on feeding concerns and advise on early communication using visual cues such as Makaton signing.

**Occupational Therapy;** will assess your child if needed for any equipment requirements and help to aid development in the early stages.

**Physiotherapy;** if required will give advice on your child's physical needs and help progress gross motor skills. You may also be referred to Orthotics once your child is weight bearing.

### Additional Information available from your Early Support Coordinator

- ✓ Early Support-Information about Down's syndrome booklet
- ✓ Breast feeding leaflet & support contact numbers
- ✓ Positions for play information
- ✓ Detailed service offer for children with Down's syndrome from:
  - Speech & Language Therapy
  - Occupational Therapy & Physiotherapy
  - Cambridgeshire County Council SEND specialist services
- ✓ Specialist Groups for children with additional needs
- ✓ Disabled Children's Social Care
- ✓ Audiology
- ✓ Special needs Community Information Point (SCIP) - Community support and activities

### Information as your child gets older:

- ✓ Cognition & learning pathway
- ✓ Education Health & Care Plan - support at school
- ✓ Preparing for Adulthood
- ✓ Special Educational Needs & Disability Information, Advice and Support Service (SENDIASS)

# Further Information

## Local Community Support Groups

- Big Journeys begin with Small Steps (Huntingdon)  
**E:** watsonalison@hotmail.co.uk
- Cambridge Babies and Children with Down's syndrome support group  
**T:** 07812 348189 (Matt or Laura)  
**E:** dssgcambridge@gmail.com

## Support organisations

- Down's Syndrome Association-supporting people with Down's Syndrome throughout their lives.  
**W:** www.downs-syndrome.org.uk/
- Eddie's-local support for people with learning disabilities  
**W:** www.eddies.org.uk
- Pinpoint - local parent support and involvement network, run by parents for parents. Details of local support groups.  
**W:** www.pinpoint-cambs.org.uk

## Local social care short break offer

You may be able to receive 'short breaks' funding for your child so that they can join in activities. As they grow up this funding may be able to help develop their independence and do enjoyable activities with other young people.

**W:** www.cambridgeshire.gov.uk/short-breaks  
**T:** 01480 379 800  
**E:** dceh@cambridgeshire.gov.uk

## Resources and Education Packs

- Down's syndrome Education International Apps and guides for parents and professionals  
**W:** www.dseinternational.org
- Using signs to aid communication  
**W:** www.makaton.org  
**W:** www.singhingshands.org.uk

## Finance

### Government financial assistance

Disability Living Allowance;  
Carers Allowance; Tax Credits  
**W:** www.gov.uk/browse/disabilities

### Benefits advice

- Papworth Trust  
**W:** www.papworthtrust.org.uk
- Disability Cambridgeshire  
**W:** www.disability-cambridgeshire.org.uk
- Disability Huntingdonshire  
**W:** www.dish.org.uk

### Grants / support funding

- Family Fund  
**W:** www.familyfund.org.uk
- Directory of potential funds  
**W:** www.disability-grants.org/

## You may also be interested in:

### Search Facebook for:

- Future of Downs
- Lose the Label
- Cambridgeshire SEN Parent/Carer Support Group
- Little Miracles
- Downs syndrome-Raising Awareness and Shifting Attitudes
- Peterborough area Down's syndrome group

### Search Google/Bing for role models:

- Karen Gaffney - Olympic swimmer and public speaker
- Sarah Gordy - Actress
- Lauren Potter - Actress
- Madeline Stuart - Model
- Tim's Place - Restaurant Owner
- Oliver Hellowell - Photographer
- Sujeet Desai - Musician
- Tazia Fawley - Artist

**Early Support**  
for children, young people and families

**Children & Young People's**  
Health Services  
CAMBRIDGESHIRE

Developed in collaboration with parents and professionals