

Friendship



Fun Family

Leicestershire  
**Down's  
Syndrome  
Group**

# DOWN'S SYNDROME

## New Parents & Pre-school

Where to get  
**INFORMATION  
HELP & SUPPORT**

### Introduction from LDSG

This leaflet is a starting point for information, help and support and is not intended to be an exhaustive list.

If there is an organisation that has helped you a lot and which might be useful to others, or if any details need updating, please contact -

#### **Leicestershire Down's Syndrome Group**

Telephone - voice mail only  
07757 800312

[www.leicesterdownsgroup.co.uk](http://www.leicesterdownsgroup.co.uk)

### Help Available

#### **City & County**

##### **Leicestershire Down's Syndrome Group**

[www.leicesterdownsgroup.co.uk](http://www.leicesterdownsgroup.co.uk)

Tel: 07757 800312

(voice mail only)

A voluntary family self support group holding coffee mornings for families, social get togethers and regular newsletter.

Meeting monthly at Nether Hall School, Netherhall Road, Leicester, LE5 1DT, on the second Friday of the month 10am-12.00 during term time, for coffee and support. Children have the use of various toys, soft play and multi sensory area.

##### **Downs Support Group Rutland**

Rutland Rotaract  
Family Support Centre,  
The Parks Nursery School,  
Barleythorpe Road, Oakham,  
LE15 6NR.

Tel: 01572 724646

For parents and carers who have a child with Down's Syndrome.

This informal group meets 6 weekly to share ideas and meet others.

##### **Steps**

40 Loughborough Road,  
Shepshed, Leicestershire,  
LE12 9DN.

[www.stepscentre.org.uk](http://www.stepscentre.org.uk)

Tel: 01509 506878

Supports children with some degree of motor learning disability or delay, from birth onwards, including children with Down's Syndrome.

Steps practices conductive education, a learning process which includes all aspects of children's development, with a weekly session with parent and child.

### Help Available

#### **InfoXchange**

[www.infoxchange.org.uk](http://www.infoxchange.org.uk)

Tel: 0116 2946043/9

Provides parents and carers of children with special needs, with wide ranging information on local services, support groups, welfare benefits etc.

On joining you receive an information pack, regular newsletter and access to website.

#### **Home-Start**

[www.home-start.org.uk](http://www.home-start.org.uk)

Free telephone information line for areas covered  
0800 0686368

Supports any family with a child under 5 years old.

A volunteer matched with a family visits weekly, giving emotional and practical help. Dependant on the availability of volunteers in an area.

#### **Specialist Health Visitor Helpline**

Tel: 0116 2256560

Monday-Friday 12.00-2.00pm

Help line for advice and information about general issues for families of disabled children.

#### **Family Fund**

[www.familyfund.org.uk](http://www.familyfund.org.uk)

Tel: 0845 1304542

A registered charity helping families with disabled children, by way of financial grants to assist with specialist toys, driving lessons, family holidays etc.

**Menphys SOS  
Special Outreach  
Service**

www.menphys.org.uk/sos  
Tel: 01455 899111

A voluntary organization covering various areas, providing family support, ensuring families have access to appropriate services, supporting claiming disability benefits, helping families co-ordinate their own services, help in accessing flexible day care with registered childminders, organising various social events and monthly support group.

**CLASP  
The Carers Centre  
Counselling Service**

www.claspthecarerscentre.org.uk  
Tel: 0116 2510999

Offers a range of services including a befriending and counselling service, benefits advice, advocacy and support, social activities, weekly drop in morning and newsletter.

**Parent and Carer's  
Council**

www.parentcarercouncil.co.uk

Sue - Tel: 07968 857598

Jane - Tel: 07870 688973

A group of parents and carers of children with disabilities/special needs who hold regular support and information sessions. Collects information and listens to views and suggestions, working with providers of services and other organizations to make a difference. Also runs *Take a Break Scheme* to help carers have a break. Newsletter available.

**Parents Support Group**

Contact Parent and Carer Council or Menphys SOS for further details.

Groups are held monthly at various locations - Loughborough, Syston, Coalville, Market Harborough, Hinckley, Castle Donington, Melton and Wigston. Representatives from Menphys SOS, Parent and Carers Council, Parent Partnership Service and a specialist health visitor attend groups.

**South Leicestershire  
Carers Service**

www.slcvcs.org.uk  
Tel: 01858 439263

Aims to provide carers with a local contact who can supply them with information, advice and support. A carers forum brings carers together for mutual support and help with applying for allowances and benefits.

**Carers' Service  
Voluntary Action  
Charnwood**

Tel: 01509 631783

Provides information about support groups, benefits and grants. There is a carers forum and a quarterly newsletter. Meetings take place in Loughborough, Shepshed and Syston.

**Speak Up**

Helen - Tel: 0116 2251353

Su - Tel: 0116 2388368

A new group being set up in Leicestershire, to offer weekly term time speech and language support groups, for children with Down's Syndrome aged 18 months to 7 years.

Available from Autumn, 2009.

**City Support  
Leicester****SNTS**

(Special Needs  
Teaching Service)

**Early Years Support  
Team**

New Parks House,  
Pindar Road, Leicester,  
LE3 9RN.

Tel: 0116 2254795

Home teaching from birth to under 5 years, supporting children with special needs and their families in the home, and in settings such as nurseries and pre-school groups.

**Parent Partnership  
Scheme.**

Tel: 0116 2575027

Gives confidential impartial advice to parents and carers with children aged 0-19, who need extra help with pre-school or school education.

**County Support  
Leicestershire****Leicestershire  
Portage Service**

Rothley House,  
Coalville Business Park,  
Jackson Street, Coalville,  
Leicestershire, LE67 3NR.

Tel: 01530 513600

Portage is a weekly home visiting service for children from birth to 5 years with special needs.

Home visitors work towards agreed targets with parents, setting daily activities to help develop children.

**STS**

(Specialist  
Teaching Service)

**Home Visiting Service**

Rothley House,  
Coalville Business Park,  
Jackson Street, Coalville,  
Leicestershire, LE67 3NR.

Tel: 01530 513640

Qualified teachers and practitioners provide a weekly home service, giving advice and charting the progress of activities of children with special needs from birth.

**The Parent Partnership  
Service**

Tel: 0116 2752097

Ensures that parents and carers of children with special educational needs have access to information, advice and guidance, to allow them to make informed decisions about their child's education.

**Leicestershire Family  
Information Service**

www.leics.gov.uk/family  
Tel: 0116 3056545

Information for families, parents and carers providing free and impartial advice, guidance and information for the whole family. Including childcare, free nursery education, parent and toddler groups, toy libraries, special educational needs, parenting information, local services and support, working tax credit etc.

## County Support Rutland

### Portage Rutland County Council Children and Young Peoples Services

Catmose, Oakham  
LE15 6HP.  
Tel: 01572 758496

From birth to five years for children with special needs. Weekly home visits, with one or more activities chosen and parents given advice on teaching. Parents keep a record of their child's progress.

### Rutland Citizens Advice Bureau.

Tel no: 01572 723012.

Provides advice and information for parents of children with special educational needs.

## Leicester

Based at New Parks House,  
Pindar Road, Leicester,  
LE3 9RN

Tel: 0116 2254795

Toy Library available to children who have an early years support teacher.

## Leicestershire

### County Toy Libraries

[www.leics.gov.uk/print/leicestershire\\_toy\\_libraries.doc](http://www.leics.gov.uk/print/leicestershire_toy_libraries.doc)

Coalville  
Tel: 01530 510515

South Wigston  
Tel: 0116 2810026

Loughborough  
Tel: 01509 412406  
& 01509 230629

Shepshed  
Tel: 01509 601146  
Enderby 0116 1751918

Melton Mowbray  
Tel: 01664 562554

Hinckley  
Tel: 01455 630831

Harborough District  
Mobile Library  
Tel: 01858 410740

Toy Libraries at various locations around the county, contact individual libraries as above.

### South Leicestershire CVS

Mel Stride  
Tel: 01858 468136

Voluntary toy library for parents, carers and childminders who are caring for children with special needs. Small fee payable.

## Rutland

Tel: 01572 724646

Based at the  
Rutland Rotaract  
Family Support Centre

Offers toys which are particularly suited to children with special needs.

The following are some of the toddler groups for children with special needs which meet up in Leicestershire.

It is also worth contacting your local Sure Start Centre or Childrens Centre to see if there are any other groups meeting up, details of which can be found on [www.surestart.gov.uk](http://www.surestart.gov.uk) .

A good website also for finding about local groups and things to do with your child such as singing groups, soft play, pre-school swimming etc is [www.netmums.com](http://www.netmums.com) .

### Little Rays of Sunshine

New Parks House,  
Pindar Road, Leicester  
LE3 9RN.

Amanda  
Tel: 0116 2254795

Meets once a month on a Monday 10.00am -12.00 during term time, for children with Downs Syndrome and their parents or carers. Toy Library and sensory room available.

### Birstall Playgroup for Children with Special Needs

Birstall Methodist Church,  
Wanlip Lane, Birstall, Leicester,  
LE4 4JS.

Deborah Hoggar  
Tel: 0116 2606309

Church  
Tel: 0116 2675690

Offers group and one to one support for parents of children 0-5 years with special needs. Parents stay if they wish, whilst children play. Monday and Friday mornings.

### Sunshine Group

Dorothy Goodman School,  
Stoke Road, Hinckley

Anne Hare  
Tel: 01455 634582

Support and playgroup for children with special needs and their parents, meets once a month on the first Tuesday morning of the month. Access to soft play and multi sensory room available.

### Family Fun

New Parks House,  
Pindar Road, Leicester  
LE3 9RN.

Tel: 0116 2254795

Available to children and parents who have an Early Years Support Teacher (City), Wednesday mornings 9.30am-11.30am during term time.

### Sunflowers

Rutland Rotaract  
Family Support Centre,  
The Parks Nursery School,  
Barleythorpe Road, Oakham,  
LE15 6NR.

Tel: 01572 724646

Offers support to parents of young children with special needs, meeting every Thursday morning during term time, at the Rutland Rotaract Family Support Centre. Various activities including swimming and speakers.

## Stay and Play Afternoons

Ashmount School,  
Beacon Road, Loughborough,  
Leicester.

Tel: 01509 268506

Meeting together various  
Wednesdays throughout term time,  
for children with special needs.

## Red Cross Special Needs Family Support Centre

54 Kenilworth Drive, Oadby,  
LE2 5LG.

Tel: 0116 2710359

Support Groups for families of  
children with disabilities.

## DSA Down's Syndrome Association

www.downs-syndrome.org.uk  
Tel: 0845 2300372

Focuses on all aspects of living positively with Down's Syndrome, and championing the rights of people with Down's Syndrome. Membership free for the first year. Regular journal, information on conferences and events and a large range of booklets and leaflets available.

DSA also runs a telephone help line on all aspects including welfare, education and health, advising new parents and anyone experiencing difficulties.

## DSMIG Down's Syndrome Medical Interest Group

www.dsmig.org.uk

Essentially for healthcare professionals, however provides some parent resources on medical concerns, book reviews and various links to other resources etc.

Also available is PCHR Down's Syndrome insert for your red book - should be provided by your health visitor.

## DHG - Down's Heart Group

www.dhg.org.uk  
Tel: 0845 1668061

Offers support and up to date information relating to heart conditions associated with Down's Syndrome, including one to one support, telephone helpline and newsletter.

## Special Kids in the UK

www.specialkidsintheuk.org

Providing information, contact and support between families of children with special needs, via a web site.

## Early Support Publications

www.earlysupport.org.uk  
Tel: 0845 6022260  
(to order publications directly)

Booklet on Down's Syndrome, Early Support Family Pack, Developmental Journal, and support materials for Down's Syndrome available on request.

## Down's Syndrome Educational Trust

www.downsed.org  
Tel: 0239 2855330

Can provide advice and information on ways to help your child achieve their potential with the latest information and teaching resources. Advice line, workshops, family weekends and groups for pre-school children. Booklet *Living with Down's Syndrome* available.

## Contact a Family

www.cafamily.org.uk  
Tel: 0808 8083555

Supports families who care for children with disabilities/special needs, providing a national helpline, fact sheets and national magazine. Can put families in touch with each other through their link service, and provides an online parent support group.

## Sign Language

Makaton  
www.makaton.org  
SignAlong  
www.signalong.org.uk

Children with Down's Syndrome generally benefit from being taught signs with the spoken word from about 6 months onward, to support delayed speech. Both Makaton and SignAlong are forms of sign language used.

## Symbol UK

www.symboluk.co.uk  
Tel: 01795 844440

Provides specialist speech and language therapy consultation services for children and adults with special needs.

Can provide individual consultation, support with statementing, 3-5 day intensive courses for children with Down's Syndrome, training for co-workers to provide speech and language support in various localities on a weekly basis.

## DSRF Down's Syndrome Research Foundation Ltd

www.dsrf-uk.org  
Tel 0208 9427906

Parent based medical research charity. Booklet *Bright Beginnings* available for new parents, also online parent support group. Fee payable to join.

## Cerebra

www.cerebra.org.uk  
Tel: 01267 244229

Helps to improve the lives of children with brain related conditions, with information and support. Services include postal lending library, quarterly newsletter, grant scheme, guide to claiming disability living allowance, fact sheets and a free telephone counselling service.