

WHAT THIS CHAPTER IS ABOUT

This chapter brings together a range of information – details of groups and organisations that parents can turn to for general help and support. You can contact all the organisations listed in this chapter direct – you don't need to be referred by one of the statutory agencies.

The chapter includes information about local groups of parents who have children with special needs, helplines that are manned by people who understand the stresses of caring for a child with special needs, organisations that can offer advice with all aspects of bringing up children in general, commercial agencies that can provide help at home, and organisations that can offer support if a child dies.

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AT THE BEGINNING

There are a number of organisations that can offer you information, advice, and emotional support when you first find out that there are concerns that your child may have a disability.

Scope

Scope has a Face 2 Face Network that offers a one-to-one parent befriending service for parents discovering that their child has a disability: for details see page 22.

The Birth Defects Foundation (BDF)

The BDF booklet *What next?* is for families who are awaiting the outcome of medical tests, or have recently received a diagnosis that their child has some form of birth defect. You can phone for a copy of the booklet, or you can download it from the BDF website.

The BDF Newlife helpline can provide a 'listening ear' as well as information.

BDF Newlife

BDF Newlife, Hemlock Way, Cannock

Staffordshire WS11 7GF

tel 01543 462777

helpline 08700 707020 Mon-Fri 9.30am-5pm

website www.bdfcharity.co.uk

HELP AT HOME

Where you can get help

Children's Services, Mencap, Scope and KIDS can all offer some help at home for families with severely disabled children (see Chapters 4 and 6). However, there are also many privately-run organisations that can provide help of all kinds at home, including domestic help, nursing care, and sitting services.

An organisation that specialises in help for families with disabled children, including those with complex needs, is SEARCH, which is based in Winchester, but covers the whole county.

SEARCH (Support, Education and Respite Care) Ltd

Unit 3 Barton Park, Eastleigh SO50 6RR

tel 023 8061 6215

The Guide to Care at Home

The free Hampshire Adult Services publication, the *Guide to Care at Home* gives details of organisations that can provide help at home. A symbol in the list of organisations indicates those that are registered to work with families who have children. The charge for help-at-home services varies according to the type of help and the time of day it is supplied (for example, it costs more to have a sitter overnight than someone to clean the house during the day).

You can get a free copy of the *Guide to Care at Home* from any Adult Services office or by phoning 0800 028 0888.

Homestart

Homestart is a national organisation that provides help at home for families with very young children who are under stress (for example, because a child has a disability). Their trained volunteers offer regular support, friendship and practical help.

For details of what is available near you contact the Regional Office.

Homestart South East Regional Office:

Room 110, T Wing, Crowthorne Business Estate
Wokingham Road, Crowthorne, Berkshire RG45 6AW
tel 01344 751628

website www.home-start.org.uk

SUPPORT GROUPS FOR PARENTS

There are many family support groups that link parents whose children have similar disabilities or problems so that they can share information and offer practical advice. Many of the organisations that are given in Chapter 7 run local groups – ring the number given for information about any groups near you.

There are also groups that are more general, and bring together parents of disabled children who live in the same area – and details of some groups are given here.

ProActive Parents (PAP)

26 The Vale, Oakley, Basingstoke RG23 7LB

tel 01256 782276 / 01256 355821

Helping Hands

Maple Ridge School, Basingstoke RG21 5SX

tel 01256 323639 (mobile 07879 473586)

Support group for parents and families of people with autism and/or Asperger's Syndrome; has a small library that people can borrow from; group meets first Wednesday of the month 1.15pm-2.45pm



Insight

Aldershot area: a group of parents supporting parents of autistic and Aspergers children meets monthly in a local pub. If you want to join them, or find out more contact Sarah 01252 332684 or Julia 01252 650528.

Autism & Aspergers Support Group

Mutual help and support, plus information about local services.

For details contact Denise: 01420 89762
email denise.cox@virgin.net

The Coffee Chill and Chat Zone (The Aldershot Garrison Special Needs Group)

Union Buildings, Aldershot, Hants
tel 01252 343753 / 01252 327752
Tues 10.15am-12.30pm and Fri 9.30am-12.30pm

Support/social group for parents and carers of special needs dependants.

Unique

16 Fury Way, Hill Head, Fareham PO14 3RN
tel 01329 315181

Support group for families whose children have rare chromosome disorders.

SCARF supporting special children and their relatives and friends

Rose Cottage, Wootton Road, Tiptoe
Lymington SO41 6FT
tel 01425 611199
website www.scarfuk.co.uk

Mutual support for families of children with special needs; organises activities for the children and their siblings. A parent must stay as well. Support group for parents.

Friend of the Family Winchester

c/o Friends Meeting House, 16 Colebrook Street
Winchester SO23 7AF
tel 01962 864466
email foffwin@hotmail.co.uk

Friends of the Family is a therapeutic group activity promoting positive changes in the lives of vulnerable or unhappy parents with their pre-school and primary age children.

Make-A-Wish Foundation UK

329-331 London Road, Camberley
Surrey GU15 3HQ
tel 01276 24127
website www.make-a-wish.org.uk

The Make-A-Wish Foundation aims to grant the special wishes of children aged 3-18 who have a life-threatening illness. You need to apply in writing, including full details and the name of your child's consultant. Applications are carefully checked and put before an advisory board. The Foundation receives about 30 applications a day.

COURSES FOR PARENTS

Special Children, Special Parents (SCSP)

A ten week group programme for parents or carers of young children with disabilities, giving parents the opportunity to meet other parents in similar situations, share experiences about being a parent of a child with special needs, and to find out about ideas and strategies to improve confidence in their own parenting.

Confident Parents, Confident Kids (CPCK)

An eight week group programme for parents or carers of young children (up to 8 years old) who would like practical advice on improving children's behaviour.

Supporting Parents of Teenagers (SPOT)

An eight week group programme for parents or carers of teenagers, who would like to improve their understanding, relationships and practical skills in managing their teenager's behaviour.

For further information contact;
County Parent Development Team, Children's Services.
tel 01962 876290
email parent.development@hants.gov.uk



SUPPORT IF YOU'RE LOOKING AFTER A CHILD WITH SPECIAL NEEDS AT HOME

Information and help

If you are looking after your disabled child at home, you are what is termed a 'carer'. There are a number of carers centres throughout the county where you can get information and advice about the help that is available for carers, and a carers helpline, which provides information and advice – and can arrange practical help in an emergency.

Carers Helpline

08457 221122 Mon-Thurs 5pm-11.30pm
Fri 4.30pm-11.30pm
weekends and bank holidays 8.30am-11.30pm

A local helpline for people living in Hampshire. Complete confidentiality; a listening ear; advice and information; practical help in an emergency.

Carers Together

For information about carers support groups in Hampshire phone 01794 519495
website www.carerstogether.org.uk

Carers Centres

Carers Centres offer contact with other carers, local information and support, and a chance to make your views known. Some have a drop-in centre, some run specialist support groups, some run coffee mornings – phone your nearest centre for details of what they can offer.

Andover 01264 835246

Basingstoke 01256 353290

Eastleigh 023 8090 2404

Fareham & Gosport 023 9250 1592

Havant & Petersfield 023 9259 5455

New Forest 01425 622588

Romsey 01794 511234

Winchester 01962 842034

A carer's assessment

You are entitled to an assessment of what help you need to go on looking after your child. There are more details in the free leaflet *Support for Carers*, which you can get by phoning 01962 847728.

Cry-Sis Support Group

B.M. Cry-sis, London WC1N 3XX
helpline 0845 1228 669 Mon-Sun 9am-10pm
website www.cry-sis.org.uk

Support for families that have excessively crying, sleepless and demanding babies.

Support for the brothers and sisters of children with special needs

If you have other children, they may find it difficult to come to terms with having a brother or sister who needs lots of attention. They may also be spending time helping you to look after their brother or sister.

Did you know that there are groups that can give siblings of special needs children support and information? See page 45 for full details.

ARE YOU A WORKING PARENT?

If you are trying – or are planning – to combine paid work with caring for a child with disabilities, you can get information about the support available from

Working Families

1-3 Berry Street, London EC1V 0AA
tel 020 7253 7243
website www.workingfamilies.org.uk

GENERAL INFORMATION AND SUPPORT FOR PARENTS

Information and help

There are a number of local and national organisations that offer information and advice for parents in general. They variously provide information and advice about the services and schemes that are available locally, the problems and situations that parents have to cope with (from toddlers' temper tantrums to teenage anarchy) and the issues that face single parents, divorced parents or step families.

Parentline Plus

24-hour helpline 0808 800 2222
website www.parentlineplus.org.uk

A freephone helpline about any aspects of parenting for anyone bringing up a child – parents, step-parents, grandparents, foster parents. Parentline Plus also runs courses for parents, and provides a range of information.

Children's Information Service

tel 0845 6021125 Mon-Sat 8.30am-5pm
website www.hants.gov.uk/childcare/cis.html

The Children's Information Service (CIS) is run by Hampshire County Council's Early Education & Childcare Unit, and provides a wide range of information, including details of local childcare, information about financial help with nursery education, advice about choosing childcare, and lists of the activities and services for children in the county.



THE CHILDREN'S LEGAL CENTRE

University of Essex, Wivenhoe Park, Colchester
Essex CO4 3SQ

Advice line 0845 456 6811

website www.childrenslegalcentre.com

A free and confidential legal advice and information service, covering all aspects of the law affecting children and young people

Hampshire Children & Families Forum

Beaconsfield House, Andover Road

Winchester SO22 6AT

tel 01962 843677

website www.hcff.org.uk

The Children & Families Forum has local branches and provides a means for parents to find out more about the services that are available, and gives them a chance to say what services are needed.

One Parent Families

255 Kentish Town Road, London NW5 2LX

helpline 0800 018 5026 Mon-Fri 9am-5pm

website www.oneparentfamilies.org.uk

Free information for lone parents on a number of issues, including maintenance, tax credits, benefits, legal rights, work, education, childcare, and holidays. Details of other organisations that may be able to help.

GETTING OUT AND ABOUT

Blue badges (parking permits)

If you have a disabled child – aged over two and under 16 – who has problems walking you can apply to Hampshire County Council for a disabled person's parking permit (a 'blue badge') on their behalf. For details see page 10.

Car adaptations

MAVIS (Mobility Advice & Vehicle Information Service)

Crowthorne Business Estate, Old Wokingham Road,

Crowthorne, Berkshire RG45 6XD

tel 01344 661000

website www.dft.gov.uk/access/mavis

MAVIS can provide information about access into a vehicle.

Shopmobility

Shopmobility schemes provide wheelchairs so that disabled people of all ages can more easily get round towns to shop or sightsee. You can get details of local schemes from the

National Federation of Shopmobility

The Hawkins Suite, Enham Place, Enham Alamein

Andover SP11 6JS

tel 08456 442446

website www.justmobility.co.uk/shop

Local transport

There are a number of local schemes that can provide transport in certain situations – for example, to get to a doctor's or hospital appointment, or to the shops.

- If you need help getting your child to **appointments** at your surgery or at the hospital, speak to your doctor or to the hospital staff where you have the appointment.
- The **British Red Cross** runs some 'transport and escort' services: phone 01962 868253 for information.
- **Local Dial-a-Ride** schemes provide transport for people who find it impossible or difficult to use public transport, usually taking people to local shopping centres. There is a standard charge per distance covered and you usually need to book well in advance. You can get details about your local scheme from Hampshire County Council Information Centres: 0800 028 0888.

'Cango' public bus services

The County Council's Cango buses run in some rural areas in the county. Cango is a demand responsive public bus service, so the buses do not have fixed routes. They have timed, regular stops, but can also pick up and drop passengers at stops that can be booked in advance. All Cango buses have easy access low floor doors, are wheelchair accessible, and can be booked to go to the door of people who have mobility problems.

Cango buses operate around Alton and Basingstoke, Andover, Burghclere, Fordingbridge and Romsey. For more information about these services phone Cango on 0845 602 4135 Monday to Friday 8am-6pm and Saturday 8am-4.30pm or visit <http://cango.hants.gov.uk>



Getting around London

The Disabled Persons' Transport Advisory Committee (DPTAC) has useful information about travel around and across London on its website at www.dptac.gov.uk/door-to-door.

[The Tube Access Guide](#) gives you information about London Underground stations that makes it easier to plan your journey. The free leaflet highlights stations with alternatives to stairs or escalators, and tells you the height of the step from platform to train. You can get a copy from underground stations, from the website at www.thetube.com or by phoning the travel advisor on 020 7222 5600.

For information about wheelchair accessible low floor buses that serve London stations phone the travel advisor on 020 7222 5600. Textphone 020 7918 3015.

Travel around the UK and overseas

- A guide to 'Rail Travel for Disabled Travellers' is available free from train stations.
- For information about sea and air travel for frail or disabled passengers you should contact individual ferries and airlines.

GROUPS DEALING WITH HEALTH ISSUES

Action for Sick Children

3 Abbey Business Centre, Keats Lane
Earlshilton, Leics LE9 7DQ
tel 01455 845600
website www.actionforsickchildren.org

Action for Sick Children works to improve the way children are treated when they are unwell. They publish a range of useful publications (for example, Helping children cope with pain, and Helping children cope with needles).

Action against Medical Accidents

44 High Street, Croydon, Surrey CR0 1YB
helpline 0845 123 23 52 Mon-Fri 10am-12 noon, 2-4pm
website www.avma.org.uk

Independent advice and information for anyone who believes they or a member of their family have/has been the victim of a medical accident.

HELP WHEN A CHILD DIES

Compassionate Friends

53 North Street, Bristol BS3 1EN
helpline 08451 23 23 04
every day 10am-4pm, 6.30-10.30pm
website www.tcf.org.uk

Parents who have experienced the death of one of their children offer friendship and understanding to parents and other family members after the death of a child. Support can be through a group or one-to-one. Publications available. The helpline is always answered by a bereaved parent, who is there to listen when you need someone to talk to.

Child Death Helpline

Great Ormond Street Hospital, Great Ormond Street
London WC1N 3JH
helpline 0800 282986
every evening 7-10pm & Mon-Fri 10am-1pm,
Weds 1pm-4pm
website www.childdeathhelpline.org.uk

The helpline is for anyone affected by the death of a child – a neighbour or a teacher, as well as members of the family. It offers emotional support and an opportunity to talk in confidence with someone who has also experienced the death of a child.

Winston's Wish

Clara Burgess Centre, Bayshill Road, Cheltenham
Gloucestershire GL50 3AW
tel 01242 515157
helpline 0845 20 30 40 5
website www.winstonswish.org.uk

Winston's Wish helps bereaved children and young people rebuild their lives after a family death. It offers practical support and guidance to families, professionals and anyone else concerned about a grieving child. Publications available.

Cruse Bereavement Care

Cruse House, 126 Sheen Road, Richmond
Surrey TW9 1UR
tel 0870 167 1677
website www.crusebereavementcare.org.uk

Offers information, support, advice, and publications.