

## Useful organisations

The organisations listed below provide a wide variety of services, advice and information relevant to children with disabilities and their carers. The Contact a Family Helpline 0808 808 3555 is able to provide further information.

### Aids and equipment

**British Red Cross**, 0844 871 1111, [www.redcross.org.uk](http://www.redcross.org.uk)

The British Red Cross has a volunteer-led medical equipment service that provides wheelchair hire and short-term loans of equipment across in the UK.

**Disabled Living Foundation (DLF)**, 0845 130 9177, [www.dlf.org.uk](http://www.dlf.org.uk)

DLF is a national charity that provides impartial advice, information and training on daily living aids, including specific information for families that have a disabled child. They have a UK-wide directory of suppliers. The DLF also has a website, self assessment, rapid access (SARA) site at [www.asksara.org.uk](http://www.asksara.org.uk)

**Fledglings**, 0845 458 1124, [www.fledglings.org.uk](http://www.fledglings.org.uk)

Fledglings is a national charity that aims to assist parents and carers of disabled children by identifying, sourcing and supplying practical, affordable products to address everyday issues.

**MedicAlert**, 0800 581 420 within the UK or 1800 581420 from Ireland,

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

A charity providing an internationally recognised life-saving identification system for people with hidden medical conditions and allergies, supported by a 24-hour emergency telephone service (from within the London Ambulance Service).

### Bereavement

**Child Bereavement Charity**, 01494 568900, [www.childbereavement.org.uk](http://www.childbereavement.org.uk)

This organisation supports families and educates professionals both when a child dies and when a child is bereaved. It also provides a national support and information service, award-winning resources and an interactive website with an online forum for bereaved families.

**Child Death Helpline**, 0808 800 6019, [www.childdeathhelpline.org.uk](http://www.childdeathhelpline.org.uk)

The Child Death Helpline is for anyone affected by the death of a child whatever the time period since the death. The helpline is staffed by volunteers, all of them bereaved parents. All volunteers are trained, supervised and supported by professional teams within Great Ormond Street Hospital for Children NHS Trust, and the Alder Hey Children's NHS Foundation Trust.

**Cruse Bereavement Care**, 0844 477 9400, Young person's helpline: 0808 808 1677  
[www.crusebereavementcare.org.uk](http://www.crusebereavementcare.org.uk), [www.rd4u.org.uk](http://www.rd4u.org.uk) (young person's website)  
Cruse Bereavement Care provides information and support to those affected by grief. It has local branches throughout the UK and a website specifically for children/young people experiencing grief.

**Compassionate Friends**, 0845 123 2304 (NI 028 77 88 016), [www.tcf.org.uk](http://www.tcf.org.uk)  
Compassionate Friends is staffed by bereaved parents, siblings and grandparents dedicated to the support and care of other bereaved parents, siblings and grandparents who have suffered the death of a child/children. They provide information, offer support through a helpline, have an online forum and a separate site for siblings.

## **Carers**

**Carers Direct – part of NHS Choices**, 0808 802 0202, [www.nhs.uk](http://www.nhs.uk)  
Carers Direct offers free, confidential information and advice from the NHS to help carers.

**Carers UK**, 0808 808 7777, [www.carersuk.org](http://www.carersuk.org)  
A UK-wide membership organisation run by carers for carers, providing information and advice to all carers.

**Crossroads Caring Scotland**, 0141 226 3793, [www.crossroads-scotland.co.uk](http://www.crossroads-scotland.co.uk)  
This organisation provides short breaks and practical support for carers in Scotland regardless of the age, disability or illness of the person receiving care.

**Carers Trust**, 0844 800 4361, [www.carers.org](http://www.carers.org)  
The Princess Royal Trust for Carers and Crossroads have merged into one organisation. The Trust is a charity providing independent carers' support services in the UK through its network of carers' centres, young carers' services and interactive websites.

## **Education**

**Advisory Centre for Education (ACE)**, 0808 800 5793, Exclusion advice line: 020 7704 9822 (24-hour answer machine), [www.ace-ed.org.uk](http://www.ace-ed.org.uk)  
ACE offers guidance and advice on all aspects of state education for compulsory school-age children including admissions, exclusions, bullying, attendance and special educational needs (SEN).

**The SEN National Advice Service**, Freephone helpline: 0808 808 3555, [www.cafamily.org.uk](http://www.cafamily.org.uk)  
The SEN National Advice Service will help families whose child may have special educational needs and will be able to provide advice and information on any aspect of their child's education.

**Independent Parental Special Education Advice (IPSEA)**, Advice line: 0800 018 4016, Tribunal helpline: 0845 602 9579, [www.ipsea.org.uk](http://www.ipsea.org.uk)  
IPSEA gives independent advice to parents who are uncertain about, or disagree with, the Local Educational Authority's interpretation of their child's special educational needs.

## **Funding**

**Family Fund**, 0845 130 4542, [www.familyfund.org.uk](http://www.familyfund.org.uk)

The Family Fund provides grants and information for families looking after severely disabled or seriously ill children in the UK, aged 17 years and under.

**Turn2Us**, 08449 744 099, [www.turn2us.org.uk](http://www.turn2us.org.uk)

Turn2us helps people in financial need gain access to welfare benefits, charitable grants and other financial help – online, by phone and face to face through their partner organisations. Their helpline provides free, confidential information given by trained professional advisers on welfare benefits entitlement and applying for grants.

## **General support organisations**

**Newlife Foundation for Disabled Children**, 01543 462 777, Nurse helpline: 0800 902 0095  
[www.newlifecharity.co.uk](http://www.newlifecharity.co.uk)

Newlife gives practical support for families with disabled children in the UK. They run an equipment service, a free helpline staffed by nurses. It also offers grants for essential medical equipment as well as promoting medical research and campaign to achieve improved services for children with disabilities.

**NHS Choices**, [www.nhs.uk](http://www.nhs.uk)

NHS Choices provides information and advice about health, illness and health services 24 hours a day, including search features to find local health services. You can speak to a nurse on the helpline if you need medical advice and help to make complaints. There are links to equivalent services in Scotland, Northern Ireland and Wales.

**NHS Direct**, 0845 46 47 (24-hour line), [www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk)

A service offering health direct and reassurance 365 days a year and 24 hours a day. The website has lots of useful information including symptom checker and advice on health living.

## **Government**

**Directgov**, [www.direct.gov.uk/en/CaringForSomeone](http://www.direct.gov.uk/en/CaringForSomeone) and  
[www.direct.gov.uk/en/DisabledPeople](http://www.direct.gov.uk/en/DisabledPeople)

Directgov is a single point of online access for information, including information for carers on money issues, care and support services, employment and carers' rights as well as information for disabled people on employment, education and learning, transport, rights and leisure.

## **Help for the armed forces**

**Soldiers, Sailors, Airmen and Families Association (SSAFA)**, 0845 1300 975, Support line: 0800 731 4880 (UK only), [www.ssafa.org.uk](http://www.ssafa.org.uk)

SSAFA is a national charity helping serving and ex-service men and women and their families, including widows and widowers in need.

## **Hospice Care**

**Together for Short Lives**, 0117 989 7820, [www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk)

Together for Short Lives brings together all those involved in children's palliative care, from

the children and families themselves to the professionals and organisations who provide the full range of care and support.

### **Umbrella organisations**

**Council for Disabled Children**, 020 7843 1900, [www.councilfordisabledchildren.org.uk](http://www.councilfordisabledchildren.org.uk)

The Council for Disabled Children is the umbrella body for the disabled children's sector in England and has links to the other UK nations.

**Genetic Alliance UK**, 020 7704 3141, [www.geneticalliance.org.uk](http://www.geneticalliance.org.uk)

A national alliance of patient organisations with a membership of more than 150 charities that support children, families and individuals with a genetic disorder. They provide a wide range of information on genetics, including a comprehensive glossary.

**National Voices**, 020 3176 0738, [www.nationalvoices.org.uk](http://www.nationalvoices.org.uk)

National Voices is a coalition of national health and social care organisations representing users of health and social care in England.

**National Parent Partnership Network (NPPN)**, 020 7843 6058,

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

Parent Partnership Services (PPS) are statutory services offering information, advice and support to parents and carers of children and young people with special educational needs (SEN). PPS are also able to put parents in touch with other local and national organisations. The services they provide are confidential and impartial.

**Family Lives**, 0808 800 2222, [www.familylives.org.uk](http://www.familylives.org.uk)

Family Lives is a national charity that works for, and with, parents with any problem around a range of issues affecting parents and their families from having a new baby, starting a new relationship and disagreements in the family, to issues with teenagers, school, homework, sleep or eating patterns.

### **Young Carers**

**Sibs**, 01535 645453, [www.sibs.org.uk](http://www.sibs.org.uk)

Sibs provides information and support for siblings and how parents can support them. In addition, they provide information and advice for professionals supporting young carers.

**Young Carers Net (YC Net)**, [www.youngcarers.net](http://www.youngcarers.net)

YCNet is a website and online support service for young people aged 18 years and under in the UK, who help to look after someone in their family who has an illness, disability, drug/alcohol addiction or mental health condition.

If problems are experienced accessing these organisations then call our freephone helpline on 0808 808 3555.

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