# **External support groups and information**

<u>Carers Scotland</u>, part of Carers UK provides expert advice, information and support. You can call the Carers UK Adviceline on 0808 808 7777, Monday to Friday 10am-4pm, for information and advice on benefits and tax credits, carers employment rights, carers' assessments, the services available for carers and how to complain effectively and challenge decisions. Calls are free from landlines and some mobile networks. See <u>http://www.carersuk.org/help-and-advice/talk-to-</u><u>us</u> for more details.

There is also a <u>Carers UK Forum</u>, an online community of carers which is available to Carers UK members 24 hours a day, 365 days a year. A few words from a fellow carer who understands what you're going through can be a lifeline. So whether you need to share an experience, ask a question or simply let off some steam, log in and join the conversation. If you're not a Carers UK member you can join now for free. See <u>http://www.carersuk.org/help-and-advice/talk-to-us</u> for more details. The Carers UK website also has helpful <u>factsheets</u>. More carers advice can also be found at:

- <u>Carers UK</u>: <u>http://www.carersonline.org.uk</u> Advice, information and campaigning for carers.
- <u>Carers Trust</u>: <u>https://carers.org/section/help-advice</u> has helpful advice and factsheets, as well as allowing you to search for local care and carer services in your area.
- <u>Crossroads Care</u>: <u>http://www.crossroads.org.uk</u> Co-ordinates schemes for care of disabled people in their own homes.
- <u>Crossroads Scotland</u>: <u>http://www.crossroads-scotland.co.uk</u> Care Attendant Schemes providing short breaks for carers across Scotland.
- <u>Princess Royal Trust for Carers</u>: <u>http://www.carers.org</u> Provides access to support, advice and services through its network of carers' centres.

## **Organisations:**

#### **Older People:**

- Age UK
- <u>Counsel and Care</u>
- Independent Age helps older people on low incomes to live with dignity and peace of mind
- <u>The Relatives & Residents Association</u> exists for older people needing, or living in, residential care and the families and friends left behind.
- <u>Action on Elder Abuse</u> AEA work to protect, and prevent the abuse of, vulnerable older adults.

#### **Disabilities:**

- <u>Alzheimer's Society</u> The UK's leading care and research charity for people with dementia, their families and carers.
- <u>Arthritis Care</u> has a dedicated website for carers.
- <u>Autism Anglia</u> provides education, care and support for people with autism and their families.

- <u>British Heart Foundation</u> Join Heart Matters today. This FREE service from us offers a unique package of support and information for people looking to improve their heart health.
- <u>Carers and Brain Tumours</u> Practical information and support for carers of people with a malignant brain tumour.
- <u>Connect</u> The Communication Disability Network is for people living with stroke and aphasia.
- <u>Disability Book</u> A database of support networks and links to helpful sites.
- <u>Epilepsy Action</u> We want to live in a society where everyone understands epilepsy and where attitudes towards the condition are based on fact not fiction.
- Fibromyalgia Support Net Information for Fibromyalgia sufferers and their carers.
- <u>Help the Hospices</u> Website for carers of people with terminal illness.
- <u>M.E. Support</u> is a friendly, informal 'online community' bringing awareness to chronic fatiguing illnesses.
- Motor Neurone Disease Association
- <u>MS Society</u>
- <u>MS Trust</u> a national charity offering information to anyone affected by MS people with the condition themselves, family, friends and those professionals who work with them.
- Muscular Dystrophy Campaign
- <u>Parkinson's Disease Society</u> The leading charity dedicated to supporting all people with Parkinson's, their families, friends and carers.
- <u>The PSP Association</u> The only charity in the UK supporting patients with Progressive Supranuclear Palsy, their carers, families and professionals within the health service.
- <u>The Stroke Association</u> The Stroke Helpline is open between 9am 5pm Monday to Friday on 0845 3033 100.

## Learning Disabilities:

- <u>Mencap</u>
- Down's Syndrome
- <u>National Autistic Society</u>
- <u>National Family Carer Network</u> for families that include an adult with a learning disability.

## Mental Health:

- <u>Rethink</u>
- Supporting Carers Better Network
- <u>Saneline</u> Mental Health Advice Line
- <u>MIND</u> How we can help you? Mind helps people take control of their mental health.
- <u>Making Space</u> Improving the long term welfare of those people who have mental health problems and those who care for them.
- Mental Health Foundation

## Sensory Impairment:

- <u>RNID</u>
- <u>RNIB</u>
- <u>Sense</u> The leading national charity that supports and campaigns for children and adults who are deafblind.

#### Children:

- <u>Contact a Family</u>
- <u>Barnardo's</u>
- National Deaf Children's Society (NDCS)
- Action for Children
- <u>ADDISS</u> Information and Support Service for parents, carers and sufferers of ADHD.
- Parentline Plus is a UK registered charity which offers support to anyone parenting a child.

## Young Carers:

- The Children's Society: National Young Carers Initiative
- Princess Royal Trust for Carers: Young Carers Site

#### Cancer:

- <u>Centres for Disease Control and Prevention</u> Cancer Prevention and Control
- <u>A blog by Steven Walker</u>, Research Coordinator of the Pancreatic Cancer Action Network - Covers cancer types, causes and treatments.
- <u>An article by the Daily Mail</u> explaining the 20 most common cancers.
- <u>Macmillan Cancer Support</u>

#### **General Disability Links:**

- <u>Disability Information Service.</u> Impartial and independent disability information to, from and across the UK.
- <u>National Centre for Independent Living</u> Promoting independent living; and promoting and supporting the use of direct payments to enable independent living.
- <u>Disabled Living Foundation</u> Provides free, impartial advice about all types of equipment for older and disabled people, from jar openers to tap turners, stairlifts to walk-in baths.
- <u>RADAR</u> Advocating for, informing and supporting disabled people.
- <u>Tourism for All UK</u> National charity that provides holiday and travel information to older and disabled people.
- <u>Holiday Homes for the Handicapped</u> A charity providing holiday accommodation for disabled people.
- <u>Disabled Access Holidays</u> features holiday destinations that are suitable for disabled travellers in a number of different countries.
- Equipment Direct A free service providing information to improve independent living for older people and those with an impairment.
- <u>Good Access Guide</u> The UK's leading directory of services for disabled people.

## **Technology and Telecare:**

- <u>At Dementia</u> user-friendly information about assistive technology for people with dementia.
- <u>Ricability</u> advice on products and services of value to older and disabled people.
- <u>Telecare Services Association</u> Links to regional and local community social alarm services.

#### Aids and Equipment:

- <u>Disabled Drivers Association</u>: <u>http://www.dda.org.uk</u> Provides information and practical help on mobility issues for disabled people.
- <u>Disabled Living Foundation</u>: <u>http://www.dlf.org.uk</u> Comprehensive information service on aids and equipment for people with disabilities.
- <u>MedicAlert</u>: <u>http://www.medicalert.org.uk</u> The Emergency Identification System for people with hidden medical conditions.

#### **Bereavement:**

- Child Bereavement Trust Web: <u>http://www.childbereavement.org.uk</u>
- <u>Child Death Helpline</u>: <u>http://www.childdeathhelpline.org.uk</u> A partnership between professionals and trained volunteers, virtually all of whom are bereaved parents, who offer befriending and emotional support to others who have suffered a similar experience.
- <u>Compassionate Friends</u>: <u>http://tcf.org.uk</u> Support for bereaved parents.
- <u>Cruse Bereavement Care</u>: <u>http://www.crusebereavementcare.org.uk</u> and <u>http://www.rd4u.org.uk</u> (Young Person's web site) – Bereavement help and information.

#### **Funding:**

- <u>Family Fund</u>: <u>http://www.familyfund.org.uk</u> A national charity offering financial assistance and information to families caring for a child/children with special needs and disabilities under the age of 16 years.
- <u>React</u>: <u>http://www.reactcharity.org</u> Grants for the special aids/equipment needs of children with life-threatening conditions.

#### **General Support Organisations:**

- <u>Barnardo's</u>: <u>http://www.barnardos.org.uk</u> Barnardo's helps the most vulnerable children and young people transform their lives and fulfil their potential.
- Family Rights Group Tel: 0800 731 1696 (Mon–Fri, 10am–3.30pm) e-mail: advice@frg.org.uk: http://www.frg.org.uk – Offer advice for parents and other family members whole children are involved with, or need, social care services.
- <u>Newlife Foundation for Disabled Children</u>: <u>http://www.newlifecharity.co.uk</u> Provides support service for families, funds medical research, creates awareness and encourages prevention of birth defects.
- <u>SSAFA</u>: <u>http://www.ssafa.org.uk</u> National charity helping serving and ex-service men, women and their families, including widows and widowers in need.
- <u>The Cedar Foundation</u>: <u>http://www.cedar-foundation.org</u> Northern Ireland charity supporting people with disabilities to be fully included in their communities.

#### **Government:**

• <u>Directgov</u>: <u>http://www.direct.gov.uk/carers</u> (information for carers) and <u>http://www.direct.gov.uk/disability</u> (information for disabled people) Directgov provides a single point of online access to government carers and disability services and information – including financial support, rights, independent living and much more. • <u>ParentsCentre Web</u>: <u>http://www.parentscentre.gov.uk</u> – Information and support for parents on how to help with your child's learning, including advice on choosing a school and finding childcare.

#### **Relationships:**

 <u>The Couple Connection</u>: <u>http://thecoupleconnection.net/</u> – Provides parents with online information, forums, personal spaces and 'couple spaces' aimed at enabling couples to improve their relationship with their partner. Includes specific information for fathers and parents of children with disabilities.

## Short-term Breaks:

Provision of Short Term Breaks varies widely. Information can be obtained from local social services and voluntary organisations such as:

- <u>Barnardos</u>: <u>http://www.barnardos.org.uk</u>
- <u>NCH</u>: <u>http://www.nch.org.uk</u>

Contact a Family national and regional offices have details of information services and providers in their area.

#### **Transition:**

<u>Progress Magazine: http://www.progressmagazine.co.uk/</u> –
Progress is a transition guide for 13 to 25 year olds with special needs with information for young adults, parents, carers and professionals.

## **Umbrella Organisations:**

- <u>ACT Association for Children with life-threatening or Terminal conditions and their</u> <u>families</u>: <u>http://www.act.org.uk:http://www.act4families.org.uk</u> – Campaigns for children's palliative care services, promotes models of good care and provides information for families and professional workers.
- <u>Brain and Spine Foundation</u>: <u>http://www.brainandspine.org.uk</u> and <u>http://www.headstrongkids.org.uk</u> (children and young people site) – Provides an information service for patients, carers and health professionals; an education programme for GPs and medical undergraduates; and workbooks for schools and colleges as well as supporting a wide range of neuroscience research projects.
- <u>Council for Disabled Children</u>: <u>http://www.ncb.org.uk/cdc</u> Promotes collaborative work between different organisations providing services and support for children and young people with disabilities and special educational needs.
- <u>Genetic Interest Group</u>: <u>http://www.gig.org.uk</u> Forum of voluntary organisations concerned with policy for genetic disorders.
- <u>Long-Term Medical Conditions Alliance</u>: <u>http://www.lmca.org.uk</u> The umbrella body for national voluntary organisations working to meet the needs of people with long-term health conditions.
- <u>National Parent Partnership Network (NPPN)</u>: <u>http://www.parentpartnership.org.uk</u> Supports the work of the parent partnership services which provide information and advice to parents, particularly during statutory assessment and the issuing of a statement.
- <u>Patients Forum</u>: <u>http://www.thepatientsforum.org.uk</u> A network of national and regional organisations representing the healthcare interests of patients, their families and carers.

• <u>Transplant Support Network</u>: <u>http://www.transplantsupportnetwork.org.uk</u> – The Network provides support and information for all those who have had a transplant.

#### **Others:**

- <u>Care2assist: http://www.care2assist.com</u> e-mail: <u>info@care2assist.com</u> A service aimed at finding home help or au-pairs for families with disabled children.
- <u>Disabled Holiday Info</u>: <u>http://www.disabledholidayinfo.org.uk</u> Information about holidays for people with disabilities including wheelchair accessible visitor attractions, activities and accommodation at selected sites around the UK.
- <u>Cafcass (Children and Family Court Advisory Support Service)</u>: <u>http://www.cafcass.gov.uk</u> Cafcass looks after the interests of children involved in family proceedings, with the aim to put children first in family courts.
- <u>Turn2us</u>: <u>http://www.turn2us.org.uk</u> Charity aimed at helping people to access money available to them through benefits, grants and other financial help.