

Support for Parent Carers

There are many organisations and charities who offer information, advice and services. If you cannot see what you are looking for or have found an organisation that has been useful to you that you would like to share, please contact us.

Children and Family Services

Tel: 01720 424490

Email: childrenservicesemail@scilly.gov.uk

Acquired Brain injury

Brain Tumour Support <https://www.braintumoursupport.co.uk/> Tel: Support Line **01454 422701** Email: info@braintumoursupport.co.uk

About: Brain Tumour Support offers support to anyone affected by any type of brain tumour.

Child Brain Injury Trust <https://childbraininjurytrust.org.uk/> There is an online contact form

About: Child Brain Injury Trust is the leading voluntary sector organisation providing emotional and practical support, information and learning opportunities for families and professionals affected by childhood acquired brain injury across the UK. There are many causes of an Acquired Brain Injury (ABI) including an accident, illnesses such as meningitis, strokes and brain tumours. It can also occur as a result of surgery to address another issue. A brain injury will affect everyone differently but often has a devastating and lifelong impact on the child and their family.

Stroke Association <https://www.stroke.org.uk/> Tel: Helpline **0303 3033 740** email: helpline@stroke.org.uk

About: Stroke Association, rebuilding lives after stroke, information and guides available on website.

Asthma

Asthma UK <https://www.asthma.org.uk/> Tel: Speak to an asthma expert nurse on our Helpline **0300 222 5800** Open Monday-Friday, 9am-5pm or visit their [contact page](#) for more ways of getting in touch.

About: Asthma UK works to stop asthma attacks and, ultimately, cure asthma by funding world leading research and scientists, campaigning for change and supporting people with asthma to reduce their risk of a potentially life threatening asthma attack. For more information visit their website.

Autism

National Autistic Society <https://www.autism.org.uk/> online contact form Tel: Autism Helpline **0808 800 4104** lines are open 10am-4pm from Monday-Thursday, Fridays 9am-3pm (excluding Bank Holidays). The Supporter Care team **0808 800 1050** is available Monday-Thursday, 10am-4pm (excluding Bank Holidays). On Fridays 9am-3pm (excluding Bank Holidays).

About: National Autistic Society is the UK's leading charity for autistic people and their families. Their goal is to help transform lives, change attitudes and create a society that works for autistic people.

Bowel & Bladder

ERIC <https://www.eric.org.uk/> Email: Online contact form Tel: Helpline **0808 169 9949** Monday to Thursday 10am to 2pm

About: ERIC, the children's bowel and bladder charity has an online information resources and also offer telephone support.

Carers Support

Isles of Scilly Parent Carers Email: iosparentcarers@gmail.com Tel: Isles of Scilly Parent Carers Co-ordinator **077892 45187**

About: The Isles of Scilly Parent Carers Group was established in 2009 and is a pro-active, independent forum of parent carers, run by parent carers, who all have children or young people with Special Educational Needs and Disabilities (SEND). As members of the National Network of Parent Carer Forums we support the development of parent carer participation, a process in which parents work together with professionals to make improvements to local services. We act as a conduit for a wide variety of local professionals in their work with children and young people with SEND.

The Isles of Scilly Parent Carer's Group's purpose is to improve the services provided for our young people, aged between 0 and 25 years.

We are a Parent Participation Forum enabling parent carers to participate in developing and influencing local services. We work with service providers, individuals and organisations to bring a real-life perspective and experience to the planning and development of the services that our families use. We focus on helping to raise the standard of Social Care, Education and Health Services within and provided to the Isles of Scilly, to ensure that these services are provided in a way that meets the needs of all disabled children and their families locally.

The Isles of Scilly Parent Carer Group aim to meet regularly to use the unique shared experiences that they have gained in raising their own families to work in partnership with all agencies responsible for providing services to children with additional needs/disabilities in the Isles of Scilly, enjoy family fun days, have social evenings out and offer a peer support network.

To become a member of the Isles of Scilly Parent Carers Group you must be a parent of a child or young person with SEND aged 0-25 and live in the Isles of Scilly. We welcome members from across our islands. Please email iosparentcarers@gmail.com to make enquiries or to request a membership form.

Carers Trust www.carers.org.uk email: info@carers.org Tel: **0844 800 4361**

About: Carers Trust has information for carers on a variety of topics and directory of services. There is a separate website area for young carers that includes: newsletter sign up, information, web chats and discussion boards.

Carers UK www.caresuk.org email: info@carersuk.org Tel: **0808 808 7777** Information and factsheets for careers.

About: Carers UK offer support for careers through an advice line, online mentoring and online forum.

Citizens Advice <https://www.citizensadvice.org.uk/> **Citizens Advice Cornwall** <https://www.citizensadvicecornwall.org.uk/>

About: Can offer a range of advice including Macmillan welfare benefits. You can get advice from Citizens Advice online, over the phone, or in person at a Local Office. Citizens Advice, Cornwall, visit Scilly on the second Thursday of every month, May to December, at the Carn Gwaval Wellbeing Centre. For further information or to make an appointment please call Isles of Scilly Council Customer Hub on 01720 424405 or the Library on 01720 424499.

If you would like advice over the phone, you can ask for a call back by texting the word ADVICE for general queries or DEBT for debt related issues, to the number 78866. Please be aware if you do this we may leave a message to say that we have called. Telephone Access Centres operate Monday – Friday, 10.00am until 4.00pm. The number to dial is 03444 111 444. When you call your details will be taken and you will receive a Gateway Assessment interview, to help assess your situation and get you the advice you need.

SIBS <https://www.sibs.org.uk/> email: info@sibs.org.uk Tel: 01535 645453

About: Sibs for brothers and sisters of disabled children and adults. Information and advice for young siblings, adult siblings, parents and professionals. Online chat forums, phone and email support services available.

Scope <https://www.scope.org.uk/> email: helpline@scope.org.uk Tel: **0808 800 3333** Monday to Friday 8am – 8pm Saturday to Sunday and most bank holidays 10am to 6pm

About: Scope is the disability equality charity in England and Wales. They provide practical information and emotional support and campaign to create a fairer society.

Cerebral palsy

Cerebra <https://cerebra.org.uk/> email: enquiries@cerebra.org.uk Tel: Helpline **0800 328 1159**

About: Cerebra is the national charity helping children with brain conditions and their families discover a better life together. They have useful information and advice and have a helpline.

Scope <https://www.scope.org.uk/> email: helpline@scope.org.uk Tel: Helpline **0808 800 3333** Monday to Friday 8am to 8pm and Saturday and Sunday 10am to 6pm and most bank holidays Text phone: Use Type Talk by dialling 18001 from a text phone followed by 0808 800 3333 and also British Sign Language video calls are available.

About: Scope is the disability equality charity and provide practical information and emotional support and campaign to create a fairer society. They have an online community and online support and advice as well as useful information. They have a helpline.

Diabetes

Diabetes UK <https://www.diabetes.org.uk/> email: helpline@diabetes.org.uk Tel: Helpline **0345 123 2399** Monday to Friday 9am to 6pm. There is online chat available.

About: Diabetes UK, the leading charity for people living with diabetes in the UK. Our vision is a world where diabetes can do no harm. The website has information about diabetes, advice and guidance.

Digibete <https://www.digibete.org/> email: hello@digibete.org Online contact form

About: **DigiBete**, a place to help young people and families to manage **Type 1 Diabetes**. DigiBete is a video platform and social enterprise created in partnership with the Diabetes Team at Leeds Children's Hospital, resources are added and updated regularly.

Downs Syndrome

Downs Heart Group <https://dhg.org.uk/> email: info@dhg.org.uk Tel: **0300 102 1644**

About: Down's Syndrome Heart Group, is a small national charity offering support and information relating to heart conditions associated with Down's Syndrome.

Downs Syndrome Association <https://www.downs-syndrome.org.uk/> email: info@downs-syndorme.org.uk Tel: Helpline **0333 1212 300** Monday to Friday 10am to 4pm

About: Downs Syndrome Association provides information and support on ALL aspects of living with Down's Syndrome to ALL who need it.

Dyslexia

The British Dyslexia Association <https://www.bdadyslexia.org.uk/> email: helpline@bdadyslexia.org.uk or use online contact form Tel: **0333 405 4555**

About: The British Dyslexia Association has information and resources to support people with Dyslexia, parents and careers, employers and teachers and professionals.

Dyslexia Cornwall <https://www.dyslexiacornwall.org.uk/> Tel: Helpline 01872 222 911 Email: enquiries@dyslexiacornwall.org.uk and online contact form

About: Dyslexia Cornwall provides support and services for dyslexic children and adults of all ages, their parents/families, educators, employers and the wider community. They provide an outreach services across the whole of Cornwall and the Isles of Scilly.

Epilepsy

Epilepsy Action <https://www.epilepsy.org.uk/> Tel: Helpline **0808 800 5050** Monday to Thursday 8.30am-8.00pm Friday 8.30am-4.30pm Saturday 10.00am-4.00pm email: helpline@epilepsy.org.uk

About: Epilepsy Action offer advice and information, there is a helpline is available.

Epilepsy Society <https://www.epilepsysociety.org.uk/> Tel: Helpline **01494 601 400** Monday and Tuesday 9am to 4pm Wednesday 9am to 7.30pm

About: The Epilepsy Society offers information and advice, there is a helpline available.

Genetic Condition

Albinism Fellowship <https://www.albinism.org.uk/> email: use on online ticket system, check website for details Tel: **07946 457979** leave a message on the answerphone and you will be called back.

About: The Albinism Fellowship is a volunteer run organisation that aims to provide information, advice and support for people with albinism and their families.

Unique – Understanding rare chromosome and genetic disorders <https://www.rarechromo.org/> Tel: Helpline **01883 723306** Email: info@rarechromo.org

About: Unique aims to facilitate a network of families across the world living with rare chromosome disorders or autosomal dominant single gene disorders, bringing them together both in person and virtually for invaluable mutual support. By networking with professionals and the wider public also aim to increase awareness and understanding of what it's like to live with these disorders. Unique is a source of information and support to families and individuals affected by any rare chromosome disorder and to the professionals who work with them. Unique is a UK-based charity but welcomes members worldwide. Membership of Unique is free

Spinal Muscular Atrophy UK <https://smauk.org.uk/> Tel: 01789 267 520 Monday to Thursday 9 am to 3.30 pm Friday 9 am to 1 pm online contact form

About: Support and information about Spinal Muscular Atrophy.

Swan UK <https://www.undiagnosed.org.uk/> email: info@undiagnosed.org.uk or online contact form

About: SWAN UK (Syndromes Without A Name) is an initiative run by the charity Genetic Alliance UK offering support and information to families of children with undiagnosed genetic conditions.

Hearing loss

Hearing Loss Cornwall <https://www.hearinglosscornwall.org/> Tel: **01872 225 868** Email: info@hearinglosscornwall

About: Hearing Loss Cornwall is a long established Cornish charity promoting inclusion and deaf awareness across Cornwall and the Isles of Scilly. Hearing Loss Cornwall can provide information, advice, training and communication support, including British Sign Language interpretation services.

National Deaf Children's Society <https://www.ndcs.org.uk/> Tel: Helpline **0808 800 8880** available Monday to Friday 9am to 5pm SMS 0786 00 22 888 Video call with BSL interpreter. An online contact form and live chat are also available. Email: ndcs@ndcs.org.uk

About: Provide independent information and guidance on a range of topics across the UK related to childhood deafness and can also provide information and guidance to professionals working with deaf children and young people on these issues.

Learning Disability

Mencap <https://www.mencap.org.uk/> Tel: Learning disability helpline **0808 808 1111** Monday to Friday 9am to 3pm

About: Mencap is a UK charity for people with a learning disability. We support their families and carers, too. They also have an online Community where you can ask questions.

Life Limited

Child Bereavement UK <https://www.childbereavementuk.org/> Tel: Helpline **0800 02 888 40** Email: support@childbereavementuk.org

About: Child Bereavement UK supports families and trains professionals both when a baby or child dies, and when a child is facing bereavement.

Cystic Fibrosis Trust <https://www.cysticfibrosis.org.uk/> Tel: Helpline 0300 373 1000 or 020 3795 2184 Monday to Friday 9.30am to 4.30pm Email: helpline@cysticfibrosis.org.uk

About: Cystic Fibrosis Trust dedicated to fight for a life unlimited for everyone affected by cystic fibrosis.

MPS Society <https://www.mpssociety.org.uk/> Tel: **0345 389 9901** Email: mps@mpssociety.org.uk

About: The MPS Society supports those affected by MPS, Fabry and related diseases. Transforming lives now and in the future.

MS Society <https://www.mssociety.org.uk/> Tel: Helpline 0808 800 8000 Monday to Friday 9am to 7pm Email: helpline@mssociety.org.uk

About: MS Society has a range of useful resources on their website and helpline.

MS-UK <https://www.ms-uk.org/> Tel: MS-UK Helpline 0800 783 0518 Online contact form

About: MS-UK is a national charity that aims to empower people with multiple Sclerosis.

Together for Short Lives <https://www.togetherforshortlives.org.uk/> Tel: **0808 8088 100** Email: info@togetherforshortlives.org.uk and online contact form.

About: Together for Short Lives aims to make a lifetime of difference for seriously ill children. Browse family resources and factsheets on their website.

Physical disability

Versus Arthritis <https://www.versusarthritis.org/about-arthritis/> Tel: Helpline **0800 5200 520** Monday to Friday 9am to 8pm Email: enquiries@versusarthritis.org

About: Versus Arthritis has a range of advice and information on their website including young people and health care professionals.

Aspire <https://www.aspire.org.uk/> Tel: **020 8954 5759** Email: info@aspire.org.uk

About: Aspire provides practical help to people who have been paralysed by Spinal Cord Injury, supporting them from injury to independence.

Ataxia UK <https://www.ataxia.org.uk/> Tel: Helpline **0845 644 0606** Monday to Thursday 10.30am to 2.30pm Email: help@ataxia.org.uk

About: Ataxia UK offer advice and information for people affected by any type of ataxia. Also fund research into finding treatments and cures.

Back Up Trust <https://www.backuptrust.org.uk/> Tel: **020 8875 1805** support service Monday to Friday 9am to 5pm Email:

outreachandsupport@backuptrust.org.uk

About: Back Up Trust offer a range of services including a support service for anyone with a spinal cord injury or their loved ones. Information advice available and support young people.

Children's Liver Disease Foundation <https://childliverdisease.org/> Tel: **0121 212 3839** Email: info@childliversisease.org Also support for young people aged 11 – 24 <https://childliverdisease.org/young-people/> Tel: 0121 212 6024 Email: youngpeople@childliverdisease.org

About: Children's Liver Disease Foundation have an extensive information hub on childhood liver disease for healthcare professionals and their families.

Cleft Lip and Palate Association CLAPA <https://www.clapa.com/> Tel: **020 7833 4883** Email: info@clapa.com CLAPA offer peer support and social media groups if you need to talk and get support. There is information on how to use this on their website <https://www.clapa.com/support/need-to-talk/>

Email: clapa.com/support or Tel: 020 7833 4883

About: Cleft Lip and Palate Association CLAPA, works to improve the lives of people born with Cleft Lip Palate and their families. CLAPA believes that every smile tells a story. From expectant parents dealing with a diagnosis to adults struggling to get the care they need, we believe that these stories and the people in them should shape everything we do.

Limbless Association <http://www.limbless-association.org/> Tel: **0800 644 0185**

About: Provides information and support to the limb-loss community

Little Hearts Matter <https://www.lhm.org.uk/> Tel: **0121 455 8982** Email: info@lhm.org.uk and online contact form.

About: Little Hearts Matter is a UK charity offering help to anyone affected by the diagnosis of single ventricle heart condition. From initial antenatal diagnosis, through treatments and into life at home, the charity works with children, young adults and families to reduce the isolation, fear and lack of understanding created when a child is diagnosed as having half a working heart. There is a youth section on their website.

Reach Charity Ltd <https://reach.org.uk/> Tel: Helpline **0845 130 6225** or 020 3478 0100 Email: reach@reach.org.uk

About: REACH is a charity that provides support and information to parents and their children affected by upper limb difference.

Scoliosis Association UK (SAUK) <https://www.sauk.org.uk/> Tel: Helpline **020 8964 1166** Monday to Friday 9.30am to 5.30pm Email: info@sauk

About: Scoliosis Association UK (SAUK) aims to provide advice, support, and information to people affected by scoliosis and their families and raise awareness of scoliosis among health professionals and the general public.

There is Teenage Hub on the website

Parkinson's UK <https://www.parkinsons.org.uk/> Tel: Helpline **0808 800 0303** Text relay 18001 0808 800 0303 Email: hello@parkinsons.org.uk aim to reply in 5 days.

About: Parkinson's UK aims to improve life for everyone affected by Parkinson's. Provide information and advice on Parkinson's including Young Onset Parkinson's.

Sensory processing

Afasic <https://www.afasic.org.uk/> Tel: Parents helpline **0300 666 9410** Monday to Wednesday 10.30am to 4.00pm or use online contact form

About: Afasic seeks to raise awareness and to create better services and provision for children and young people with speech and language impairments. Information resources are available on website.

Dyspraxia Foundation <https://dyspraxiafoundation.org.uk/> Tel: Helpline **01462 454986** Monday to Friday 9am to 1pm email:

info@dyspraxiafoundation.org.uk

About: Dyspraxia Foundation has information resources available on website.

Spina bifida

SHINE <https://www.shinecharity.org.uk/> online contact form available

About: SHINE offer information and advice for individuals and families who have a member with Spina bifida and/or hydrocephalus.

Stammering

The British Stammering Association <https://stamma.org/> email: help@stamma.org Tel: Helpline: **0808 802 0002** weekdays 10 am to 12 noon 6 – 8 pm

About: British Stammering Association (BSA) offers support to all whose lives are affected by stammering.

Vision loss

Be My Eyes <https://www.bemyeyes.com/>

About: Be My Eyes is a free mobile app designed specifically to bring sight to the blind and visually impaired. Be My Eyes connects blind and visually impaired individuals to sighted helpers from all over the world through a live video call. The app is easy to use and allows you to have sight on demand, so whenever you need visual assistance, our sighted helpers are here for you. Be My Eyes has grown to become the largest global online community for the blind and visually impaired. The app is now used in 150 countries, with visually impaired individuals being assisted by sighted helpers. Every day, helpers lend their eyes to solve challenges both big and small in the lives of the blind and visually impaired.

DeafBlind UK <https://deafblind.org.uk/> Tel: Call or use text phone **01733 358100** National Centre for Deafblindness, John & Lucille van Geest Place, Cygnet Road, Hampton, Peterborough PE7 8FD.

About: Deafblind UK is a membership organisation of, and governed by, people who are deafblind or have both a sight and hearing loss. They champion the rights and interests of all people who are deafblind or have a combined sight and hearing loss and deliver quality services to give these individuals autonomy and control over their lives. They support equality, independence and choice. There is information, advice and guidance available or someone to call if you are feeling low.

Guide Dogs <https://www.guidedogs.org.uk/> Adult services 0345 143 0229, Children and young people's services 0800 781 1444 Email: cypservices@guidedogs.org.uk General enquiries 0118 983 5555 The Guide Dogs for the Blind Association, Hillfields, Burgfield Common, Reading, Berkshire RG7 3YG

About: Guide Dogs provide a range of services with and help thousands of people who are registered blind or partially sighted to lead confident, independent and fulfilling lives.

iSightCornwall <https://www.isightcornwall.org.uk/> Tel: **01872 261110** email: info@isightcornwall.org.uk iSightCornwall, The Sight Centre, Newham Road, Truro TR1 2DP

About: iSightCornwall is for all in Cornwall and the Isles of Scilly who are affected by sight loss, whatever their age, circumstance or condition. Provide a number of services, information and advice.

Listening Books <https://www.listening-books.org.uk/> Tel: **020 7407 9417** email: info@listening-books.org.uk

About: Listening books is a membership service from £20 per year. You can join if you have an illness, physical or learning disability or mental health condition that impacts on your ability to read or hold books. Their library has fiction and non-fiction titles for both adults and children and supports the National Curriculum from Key Stage 2 to A-level with many texts and study guides.

Royal National Institute of Blind people RNIB <https://www.rnib.org.uk/> Tel: Helpline **0303 123 9999** also an online form. Email: helpline@rnib.org.uk

About: RNIB offer practical and emotional support to those affected by sight loss.

Seeing AI This is a free app and is available on IOS and Android devices from app stores.

About: Seeing AI is an app that describes the people, text and objects around you by using your phone camera. It is an ongoing research project and features change and update.

St. Mary's Library <https://www.scilly.gov.uk/learning-leisure/library-0> Tel: **01720 424499** Email: library@scilly.gov.uk

About: There are a range of large print and audio books available, talk to the librarian for further details.