

7. Useful Resources and Organisations

National Neurological Charities

Essential support & information from national sources. Discovering you are not alone can be so important. There is an extensive network of neurological charities offering support and information.

Neurological Condition	National Charity Details
Acoustic Neuroma Vestibular Schwannoma	British Acoustic Neuroma Association www.bana-uk.com Tel: <u>01246 550011</u>
Alzheimer's	Alzheimer's Society www.alzheimers.org.uk Tel: 0300 222 1122
Aphasia	Connect: www.ukconnect.org Tel: 020 7367 0840 Asphasia Now http://www.aphasianow.org/ Contact: online form Asphasia Alliance http://www.aphasiaalliance.org/
Ataxia (including Friedrich's Ataxia)	Ataxia UK https://www.ataxia.org.uk/ Tel: 020 7582 1444
Ataxia-Telangiectasia Louis-Bar Syndrome	Ataxia-Telangiectasia Society: www.atsociety.org.uk/ Tel: 01582 760 733
Autism	The National Autistic Society www.autism.org.uk/ Tel: 0808 800 4104
Bells Palsy	www.bellspalsy.org.uk/
Brain Aneurysm (unruptured)	see subarachnoid haemorrhage
Brain Haemorrhage	see subarachnoid haemorrhage
Brain Injury (Acquired)	UK Acquired Brain Injury Forum www.ukabif.org.uk Tel: 0845 608 0788 and 0345 6080788 Headway- see below
Brain Tumour	The Brain Tumour Charity www.thebraintumourcharity.org/about-us/contact/ Tel: 0808 800 0004
Cavernoma - Cerebral cavernous malformations Cavernous angioma	Cavernoma Alliance UK https://www.cavernoma.org.uk/ Tel: <u>01305 213876</u>
Cerebral Palsy	Scope www.scope.org.uk/home Tel: 0808 800 3333
Charcot Marie Tooth Disease	CMT UK www.cmt.org.uk/ Tel: 0800_6526316
Chronic Fatigue Syndrome:	See ME
Creutzfeldt-Jakob disease	CJD Support Network www.cjdsupport.net/ Tel: 01630 673973
Dementia	Dementia UK: www.dementiauk.org Tel: 020 7697 4160 Admiral Nurses Tel: 0800 888 6678 direct@dementiauk.org
Dysphasia	Speakability Since 2015 has become part of the Stroke Association www.speakability.org.uk Tel: 020 7566 1516
Dyspraxia	Dyspraxia Foundation Tel: 01462 455 016 or 454986 www.dyspraxiafoundation.org.uk/
Dystonia	The Dystonia Society www.dystonia.org.uk Tel: 020 7793 3650

Encephalitis	The Encephalitis Society: www.encephalitis.info Tel: 01653 692583
Epilepsy	Epilepsy Action www.epilepsy.org.uk Tel 0808 800 5050 Epilepsy Society www.epilepsysociety.org.uk Tel 01494 601 300/ 400
Essential tremor	National Tremor Foundation: www.tremor.org.uk Tel: 01708 386399
Fibromyalgia	Fibromyalgia Action UK www.fmauk.org.uk/ Tel: 0844 887 2444
Guillain Barré Syndrome	Guillain Barré Syndrome Support Group: www.gaincharity.org.uk/ Tel: 0800 374803
Headway	Headway www.headway.org.uk Tel: 0800 800 2244
Hemifacial Spasm	www.patient.co.uk/health/hemifacial-spasm-leaflet www.dystonia.org.uk Helpline: 020 7793 3650
Hemiparesis	HemiHelp www.hemihelp.org.uk Tel: 0345 123 2372
Hereditary Sensori-Motor Neuropathies	See Charcot Marie Tooth Disease
Huntington's Disease	Huntington's Disease Association www.hda.org.uk Tel: 0151 331 5444
Hydrocephalus	See Spina Bifida
Joubert Syndrome K	Joubert Syndrome UK www.jsuk.org/ Tel: 07530 254743
Ménière's Disease	Ménière's Society www.menieres.org.uk T el: 01306 876883
Meningitis	Meningitis Trust: www.meningitisnow.org/ Tel 0808 80 10 388
Mental Health	www.mind.org.uk/ Tel: 0300 123 3393 www.mentalhealth.org.uk/ www.mentalhealthintheuk.co.uk/
Migraine	Migraine Trust: www.migrainetrust.org Tel: 020 7631 6970 Migraine Action: www.migraine.org.uk Tel: 08456 011033
Motor Neurone Disease	MNDA Association www.mndassociation.org/ Tel: 01604 250505
Multiple Sclerosis (MS)	MS Society www.mssociety.org.uk Tel: 0808 800 8000
Multiple System Atrophy	Multiple System Atrophy Trust: www.msatrust.org.uk Tel: 0333 323 4591
Muscular Dystrophy	Muscular Dystrophy UK www.muscular-dystrophy.org Tel: 020 0800 652 6352
Myalgic Encephalomyelitis Myalgic Encephalopathy ADEM (Acute Disseminated Encephalomyelitis)	ME Association: www.meassociation.org.uk Tel: 01280 818968
Myasthenia Gravis and other Myasthenia Conditions	Myaware (formerly Myasthenia Gravis Association): Tel: 01332 290219 Email: info@myaware.org Website: www.myaware.org

Narcolepsy	Narcolepsy UK www.narcolepsy.org.uk Tel: 0845 450 0394
Neurofibromatosis	The Neuro Foundation www.nfauk.org Tel: 020 8439 1234
Pain and Pain Management	Pain UK
Parkinson's Disease	Parkinson's UK: www.parkinsons.org.uk Tel: 0808 800 0303
Polio and Post-polio Syndrome	British Polio Fellowship www.britishpolio.org.uk/ Tel: 0800 043 1935
Progressive Supranuclear Palsy	The PSP Association www.pspeur.org Tel: 0300 0110 122
Raynaud's Syndrome	Scleroderma and Raynaud's UK https://www.sruk.co.uk/ Tel: 0800 311 2756
Rett Syndrome	Rett UK http://www.rettuk.org/ Tel: 01582 798911
Spina Bifida	Spina bifida hydrocephalus Association is now known as SHINE www.shinecharity.org.uk/ Tel: 01733 555988
Spinal Cord Injury	Aspire: www.aspire.org.uk Tel: 020 8954 5759 Spinal Injuries Association: www.spinal.co.uk Tel: 0800 980 0501 or 01908 604 191
Spinal Muscular Atrophy (SMA)	The SMA Trust www.smatrust.org Tel: 01789 801155
Spinal Tumour	Brain and Spine Foundation: www.brainandspine.org.uk Tel: 0808 808 1000
Stroke	The Stroke Association: www.stroke.org.uk Tel: 0303 3033 100
Subarachnoid Haemorrhage	Brain and Spine Foundation: Tel: 0808 808 1000 www.brainandspine.org.uk
TIA	See Stroke
Tourettes Syndrome	Tourettes Action: www.tourettes-action.org.uk Tel: 0300 777 8427
Transverse Myelitis	The Transverse Myelitis Society: www.my.elitis.org.uk
Tremor	National Tremor Foundation (NTF) http://www.tremor.org.uk/ Tel: 01708 386399
Trigeminal Neuralgia	Trigeminal Neuralgia Association UK http://www.tna.org.uk/index.php Tel: 01883 370214
Tuberous Sclerosis	Tuberous Sclerosis Association: www.tuberous-sclerosis.org
Wilson's Disease	Wilson's Disease Support Group UK www.wilsonsdisease.org.uk/

'The journey of a thousand miles begins with one step.'
Lao Tzu

Regional and Local Groups

Many neurological conditions are uncommon or rare. Not all are included here and may not have local contacts. Also check National Groups. If you see any gaps please let us know.

ALZHEIMERS SOCIETY - Central West Area

Area: Berkshire (Reading), Buckinghamshire (Milton Keynes), Hampshire (Portsmouth, Southampton), Channel Islands, Isle of Wight and Oxfordshire (Oxford).

Address: Alzheimer's Society, 118- 128 London Street, Reading, Berkshire RG1 4SJ
Telephone: 0118 959 6482 **Email:** ese@alzheimers.org.uk

Area: Basingstoke & Petersfield Office Alzheimer's Society Ground Floor Room 3
8 Chequers Road, Basingstoke, Hampshire RG21 7PU
Telephone: 01256 363 393 **Email:** basingstoke-district@alzheimers.org.uk

Area: Portsmouth & South East Hampshire, Alzheimer's Society, Rooms 02RF28 & 03RF32, John Pounds Centre, 23 Queen Street, Portsmouth, Hampshire PO1 3HN
Telephone: 02392 892 035 **Email:** portsmouth@alzheimers.org.uk

Area: Southampton & Eastleigh Office, Alzheimer's Society, 40 Chamberlayne Road, Eastleigh, Hampshire SO50 5JH
Telephone: 02380 610 159 **Email:** southampton@alzheimers.org.uk

APHASIA

Asphasia Now, but has no regional groups <http://www.aphasianow.org/> **Contact:** [online form](#)

Asphasia Alliance <http://www.aphasiaalliance.org/>

Connect: www.ukconnect.org **Regional Group:** Christchurch Helen Mann Tel: 020 7367 0864
Email: helenmann@ukconnect.org

ATAXIA UK

Hampshire Support Group 75 Keyhaven Road, Milford on Sea, Lymington, Hampshire SO41
Telephone Contact Jenny Rose Tel: 01590 645739 **Email:** aandbmorris@gmail.com

AUTISM Hampshire

Head Office 1634 Parkway, Solent Business Park, Whiteley, Fareham, Hampshire, PO15 7AH
Tel: 01489 880881 www.autismhampshire.org.uk/contact-us.html

Community Access - Information, Advice, Projects.

Community Access - Southampton, Suite 1c, Fairways House, Mount Pleasant Road, Southampton, Hampshire, SO14 0QB Tel: 02380 633951

Email: communityaccess@autismhampshire.org.uk

Community Access - Portsmouth, Frank Sorrell Centre, Prince Albert Road, Southsea, Hampshire, PO4 9HR Tel: 02392 814 723

For more information on our Community Access please click [here](#).

Services for Adults Residential Care, Support Packages.

Anglesey Lodge, Anglesey Road, Alverstoke, Gosport, Hampshire, PO12 2DX

Tel: 02392 524243 **Email:** adultservices@autismhampshire.org.uk

For more information on our Services for Adults please click [here](#).

Domiciliary Support Services Supported Living, Employment and Education Support...

1634 Parkway, Solent Business Park, Whiteley, Fareham, Hampshire, PO15 7AH

Tel: 01489 880881 Ext 5 **Email:** domcare@autismhampshire.org.uk

For more information on our Domiciliary Services please click [here](#).

BRAIN TUMOUR

Brain Tumour Charity UK www.thebraintumourcharity.org/

Support and Info Tel: 0808 800 0004 **Email:** support@thebraintumourcharity.org

Regional Group Hampshire and Surrounding Areas contact Penny Spurr, Brain Tumour Support Worker, Tel: 07711 597166 / 0845 450 1039 or by email at penny@braintumoursupport.co.uk

BRAIN AND SPINE

Brain & Spine Foundation, LG01, Lincoln House, Kennington Park, 1-3 Brixton Road, London SW9 6DE Tel: 020 7793 5900 Email: info@brainandspine.org.uk
Helpline Tel 0808 808 1000 Email: helpline@brainandspine.org.uk

CEREBRAL PALSY

For more information regarding any services within Hampshire please contact us 01256 328329 or email romanhouse@scope.org.uk to discuss your needs further.

CHARCOT MARIE TOOTH

CMT United Kingdom, 3 Groveley Road, Christchurch BH23 3HB
Freephone: 0800 6526316 Tel: 01202 474203 info@cmtuk.org.uk Email: enquiries@cmt.org.uk
Hampshire Group Coordinator: Terry Dean 023 8055 9307 Email: terry@cmtuk.org.uk

CHRONIC FATIGUE See ME

CORTICO BASAL DEGENERATION (CBD)

Hampshire Contact Louise Roberts-West Tel: 07721 073 342
Email: jockandloubby@googlemail.com
National Helpline on 0300 0110 122 or helpline@pspassociation.org.uk

DYSPHASIA

Speakability (Action for Dysphasic Adults) In April 2015, Speakability (Action for Dysphasic Adults) became part of the Stroke Association.

240 City Road, London EC1V 2PR Tel: 020 7566 1516 **Information Service and Helpline:**
Tel: 080 8808 9572. Email: melanie.derbyshire@stroke.org.uk

In Hampshire there is a local group in Farnborough. Please contact London office for more details. If there is no Group where you live and you are interested in forming one, please contact Melanie Derbyshire on **020 7261 9572**.

DYSTONIA

Dystonia Society 2nd Floor, 89 Albert Embankment, Vauxhall, London SE1 7TP
Helpline: 020 7793 3650 Office: 020 7793 3651 Email: info@dystonia.org
Hampshire local group in Wickham, East Hants, run by volunteers.
Contact Peter Cole 0845 899 7120. Email: info@dystonia.org

ENCEPHALITIS

Tim Bond, Regional Representative Volunteer based in Hampshire area provides local support and information to people affected by Encephalitis, their families and friends. For more information or how to get in touch please visit website www.encephalitis.info contact 01653 692583 or email: support@encephalitis.info

EPILEPSY

Epilepsy Society Chesham Lane, Chalfont St Peter, Buckinghamshire SL9 0RJ
Tel: 01494 601 300 Helpline: 01494 601 400 www.epilepsysociety.org.uk/

Epilepsy Action New Anstey House Gate Way Drive Yeadon, LEEDS LS19 7XY

Phone: 0113 210 8800

www.epilepsy.org.uk

HEADWAY

Headway National www.headway.org.uk

Network support coordinator Hayley Cook, tel:07826 855811

Headway Southampton 120 Commercial Road, Totton, Hampshire, SO40 3AD

Tel: 023 8086 2948 Web: <http://www.headway-southampton.org.uk>

Headway Basingstoke Headway House, Homefield Way, Basingstoke, Hampshire RG24 9SP

Service Manager Heather Jury Tel: 01256 314969 Email: hjury@headwaybasingstoke.org.uk
Headway Portsmouth and South East Headway Portsmouth & South-East Hants, Mountbatten Centre, Grandstand Suite Mountbatten Centre Twyford Avenue, Portsmouth PO2 9QA
Service Manager Deborah Robinson Tel: 023 9266 4972
Email: deborah@headwayportsmouth.co.uk Website: www.headwayportsmouth.co.uk
Headway Isle of Wight Tel: 01983 874651 Email: hnowsecretary@gmail.com

HEMIPLEGIA

Joanna Griffin, Home Visitor (SOUTHERN ENGLAND and Wales) - joanna@hemihelp.org.uk
http://www.hemihelp.org.uk/families/useful_contacts/local_groups/joining/
Tel: 0345 123 2372 / helpline@hemihelp.org.uk

HUNTINGTON'S DISEASE ASSOCIATION

Regional Care Advisor (Hants, Berks, IoW) <http://hda.org.uk/>
Eve Payler Tel: 023 8061 2218 Email: eve.payler@hda.org.uk
Hants and IoW Branch: <http://www.facebook.com/Huntingtons-Disease-Association-Hampshire-and-Isle-of-Wight-Branch-1258972890798592>

M.E. ASSOCIATION

Local support groups <http://www.friendswithme.org.uk/>
<http://www.meassociation.org.uk/information-and-support-line/find-a-local-support-group/>
Hampshire-wide including IoW Hampshire Friends with M.E., c/o The Community Centre, Brinton Lane, Hythe, Southampton SO45 6DU Tel: 0845 834 0325
Email: membership@friendswithme.org.uk

MENINGITIS

Sonja Butler, Community Support Officer, SOUTH AND SOUTH EAST ENGLAND
www.meningitisnow.org/how-we-help/local-support/south-and-south-east/
Call Sonja on 0845 340 2454 or Email: sonjab@meningitis-trust.org to arrange a home visit or to talk about how we can help you.
Meningitis Now - Head Office, Fern House, Bath Road, Stroud, Gloucestershire GL5 3TJ,
Tel: 01453 768000 Email: info@meningitisnow.org
Lucie Riches Community support officer, mostly covering the East of England, London and South-East. If you, or someone close to you, has been affected by meningitis, Lucie will be on hand to provide a listening ear, information and support. Tel: 0345 340 2453
Mobile 07587 554848 Email lucier@meningitisnow.org [Central and East Facebook page](#)

MOTOR NEURONE DISEASE

Motor Neurone Disease Association Tel: 01604 250505 www.mndassociation.org
Hants, Dorset, IoW, Channel Isles South Central
Regional Officer - Louise Rickenbach Email: louise.rickenbach@mndassociation.org
Tel: 03453 751831 or 0777 4268931 MND Connect 0808 8026262
Local support groups
Southampton / Winchester Contact Mrs_rocket@hotmail.com Tel 023 8089 1842
Basingstoke Contact: mndconnect@mndassociation.org Tel 0808 8026262
Portsmouth Contact: andrew.lane72@sky.com Tel 01489 790978
Regional Delivery Manager Hilary Fairfield, , 03453 751858
Regional Contacts for Hants and IoW
<http://www.mndassociation.org/get-involved/volunteering/volunteer-zone/your-staff-contacts/staff-contacts-in-the-south-east-and-thames-valley/staff-contacts-portsmouth-and-south-east-hants-group/>
Regional Contacts for North Hants
<http://www.mndassociation.org/get-involved/volunteering/volunteer-zone/your-staff-contacts/staff-contacts-in-the-south-east-and-thames-valley/staff-contacts-north-hampshire/>

MULTIPLE SCLEROSIS

Local Network Officer working for the MS Society in Hampshire & IOW :David Light – phone 02084380780, mobile 07717277498 email david.light@mssociety.org.uk

NHS MS coordinator in Southampton is sarah.gibbs2@uhs.nhs.uk

There are ten branches of the MS Society across Hampshire and the Isle of Wight - please go to the website for details www.mssociety.org.uk based in Andover, Alton & Petersfield, Basingstoke, Farnborough, Gosport & Fareham, Isle of Wight, Lyminster, Portsmouth, Southampton and Winchester

MULTIPLE SYSTEM ATROPHY

Support for you <http://www.msatrust.org.uk/support-for-you/> Tel: 0333 323 4591

Emma Rushton **Information and Services Manager**, Multiple System Atrophy Trust^[1]_[SEP]

Direct line: 0203 621 1348 ^[1]_[SEP] www.msatrust.org.uk, emma.rushton@msatrust.org.uk

Samantha Pavey Specialist Nurse Tel: 0203 371 0003 / samantha.pavey@msatrust.org.uk

Jill Lyons Specialist Nurse Tel: 01934 316 119 / jill.lyons@msatrust.org.uk

Dorset Support Group – Contact the MSA Trust office on 0333 323 4591 or support@msatrust.org.uk for more information.

Wiltshire Support Group - Contact the MSA Trust office on 0333 323 4591 or support@msatrust.org.uk for more information.

People in Hampshire may well attend our Surrey or West Sussex support groups too – Information on these can be found on our website www.msatrust.org.uk

MUSCULAR DYSTROPHY - No local group but on line discussion groups and support

www.muscular-dystrophy.org/how_we_help_you/care_and_support

<http://www.musculardystrophyuk.org/get-the-right-care-and-support/people-and-places-to-help-you/peer-support/>

South East Coast Muscle Group: Tel: 020 7803 4845 Email: m.rees@musculardystrophyuk.org

Also at Muscular Dystrophy Campaign Tel 020 7803 4800 Email: info@muscular-dystrophy.org

MYASTHENIA GRAVIS AND OTHER MYASTHENIA CONDITIONS now MYAWARE

Myaware National (Derby) (formerly Myasthenia Gravis Association):

Myaware Hampshire Support Group Contact details from : 01332 290219,

Email: info@myaware.org Website: www.myaware.org/about-myaware

NHS Specialist Nurse (Hants, IOW, Dorset, Channel Islands)

Lisa Joyce Email: myasthenia@uhs.nhs.uk

NEUROFIBROMATOSIS

We employ a network of Specialist Advisors based within NHS Trusts around the UK. To see if there is one in your area, please call us on 020 8439 1234 or [click here](#) for information about them and their work.

Rosemary Ashton – National Telephone Helpline – 07866 946 334

Carolyn Redman - South of England Local contact, based in Southampton and covering

Hampshire, Dorset, West Sussex, IoW Tel: 020 8439 1234

www.nfauk.org/about-us/specialist-advisors

PARKINSON'S DISEASE

Parkinson's UK has 3 local advisors covering Hampshire and Isle of Wight.

0808 800 0303 or www.parkinsons.org.uk for local contact details.

There are Local Branches in Alton, Andover, Basingstoke, Fareham, Hayling Island, Isle of Wight, New Forest, Portsmouth, Romsey, Southampton and Winchester there are also separate groups for younger sufferers.

SPINA BIFIDA

Southern Region Shine, Grove House, Suite 1a, London Road, Halstead, Kent TN14 7DS

Telephone: 01959 534618 E-mail: contact@shinecharity.org.uk

Naomi Marston Regional Development Manager Telephone: 01959 534618

Email: naomi.marston@shinecharity.org.uk Facebook: [Shine.Naomi.Marston](https://www.facebook.com/Shine.Naomi.Marston)

Shine South Web: www.shinesouthcharity.org

Lorraine Norman (Vice Chair) Tel: 07826 524673 Email : shinesouthcharity@gmail.com

Erica Maggs (Sec) Tel: 01329 317494 / 07858 686286 shinesouthcharity@gmail.com

SPINAL CORD INJURIES

Spinal injuries Association (SIA) South

Peer Support Officer for South Coast Steve Brookes Tel: 07535 590510

Email s.brookes@spinal.co.uk. General info Tel: 01908 604191,

Advice Line Tel: 0800 980 0501 OR [CHAT ONLINE](#)

Outreach Team www.spinal.co.uk/page/outreach-team

Websites by SIA members <https://www.spinal.co.uk/your-community/websites-by-sia-members/>

STROKE

Helpline 030 3303 3100

Stroke Association 02380 720420 HantsStrokeSupport@stroke.org.uk

Esme Mutter, Head of Stroke – South 02380 720426 esme.mutter@stroke.org.uk

Stroke Association Communication Support in Hampshire:

hantscommunicationsupport@stroke.org.uk

New Forest: Yvonne Hobbs 07515 596867 yvonne.hobbs@stroke.org.uk

West Hants: Graham Wake 07717 275773 graham.wake@stroke.org.uk

North East and

North Central Hants: Sam Malkin 07764 905151 sam.malkin@stroke.org.uk

Portsmouth and

South East Hants: Carly Davey 07717 275850 carly.davey@stroke.org.uk

Southampton and

Central Hants: Suzie Maidment 07717 275818 suzie.maidment@stroke.org.uk

Other Stroke Association services in Hampshire:

Stroke Recovery Service, Portsmouth

Debby Lewis 07505 269845 debby.lewis@stroke.org.uk

Venita Symmons 07712 326997 venita.symmons@stroke.org.uk

6 Month Review Service, Portsmouth

Mandy Souter 07515 6596920 mandy.souter@stroke.org.uk

There are 25 Stroke Clubs and Voluntary led groups across Hampshire and the Isle of Wight.

To search for your nearest club or group: www.stroke.org.uk/support/search

For services on the Isle of Wight please see page 66

TOURETTES

Hampshire, IoW, Surrey, Sussex Email: emma@tourettes-action.org.uk

<http://www.tourettes-action.org.uk/8-find-support.html>

<http://www.tourettes-action.org.uk/10-ta-groups.html?75#regiondetails>

Isle of Wight Support Organisations

ACQUIRED BRAIN INJURY

Headway IoW Local branch Joy Cleightonhills 01983 874651 hiowsecretary@gmail.com
NHS Specialist nurse in Southampton is Miranda.Gardner@uhs.nhs.uk

ALZHEIMERS SOCIETY

Isle of Wight - covered by Portsmouth Office - Rooms 02RF28 & 03RF32, John Pounds Centre, 23 Queen Street, Portsmouth, Hampshire PO1 3HN
Tel: 02392 892 035 Email: portsmouth@alzheimers.org.uk

ALZHEIMER CAFÉ UK

IOW Branch - Health conditions covered - Dementia – all types
Contact: Maggie Bennett Tel: 01983 220200 Email: alzheimercafeiow@btconnect.com
www.alzheimercafeiow.org.uk Facebook – AlzheimerCafeIOW Twitter - @AzCafeIOW

ATAXIA IOW Support Group Alan Reed 01983 867946 Email: punkyal1970@gmail.com

AUTISM INCLUSION MATTERS (AIM) GROUP

Tel: 01983 523000 - ask to speak to the AIM coordinator. Email: aimisleofwight@gmail.com
AIM is an Isle of Wight group for adults (over 18) who have Autism or Aspergers, also known as an Autistic Spectrum Disorder (ASD) or Autistic Spectrum Condition (ASC). It is not a group for parents, carers or professionals. AIM is a user led group. This means that with support, people with ASD will decide what happens in the group and help to run it. It aims to help people with ASD who may feel lonely, find it difficult to meet people or make friends. Group members choose where to meet and the range of activities to do. They support members to find people with shared interests and build friendships. There is advocacy support to listen to what adults with ASD have to say about life on the Isle of Wight, and to make changes.

BRAIN TUMOUR

Support groups meets last Tues of each month at Wessex cancer trust Support Centre, 19- 21 Lugley St, Newport PO30 5HD

CHARCOT MARIE TOOTH - see Neuromuscular Diseases

DIFFERENT STROKES, Isle of Wight

Contact: Sue Preater Tel: 01983 533236 Email: isleofwight@differentstrokes.co.uk
Exercise classes for younger stroke survivors held at Laidlaw Hospital, St Mary's Hospital, Newport. Classes are a great opportunity to meet and share experiences with other stroke survivors. Classes are designed to accommodate a wide range of abilities and medical conditions. You can join at any time and attend as many sessions as you like. You can bring a carer or partner with you. The group is run by stroke survivor volunteers. (Also see Stroke below)

EPILEPSY

David Piggott IoW Coordinator Tel: 01983 405825 Email: davepiggott65@outlook.com
Patients with Epilepsy and families are welcomed by the Headway group even without a brain injury causing their epilepsy.

FIBROMYALGIA

Self-help support group meets in Ryde. Contact: Karen Smith Tel: 0844 887 2346
Email: iwfmsg.fibromates@gmail.com www.isleofwightfibromyalgia.webs.com
Facebook Fibromates-Isle of Wight Fibromyalgia Support Group
Health conditions covered - Fibromyalgia, Chronic Fatigue Syndrome, ME

HEADWAY ISLE OF WIGHT

Isle of Wight - Small Branch run by unpaid volunteers
Riverside Centre The Quay, Newport PO30 2QR Tel: 01983 874651
Email: hiowsecretary@gmail.com

HUNTINGTONS

Regional Care Advisor (Hants, Berks, IOW) eve.payler@hda.org.uk Tel: 02380 612218
annette@scivier.uk

Several IOW families meet with Hampshire Branch.

Hants and IoW branch: <https://www.facebook.com/Huntingtons-Disease-Association-Hampshire-and-Isle-of-Wight-Branch-1258972890798592>

MOTOR NEURONE DISEASE

Motor Neurone Disease Association, Isle of Wight branch

Contact: Maureen Martinez / Ann Marchant Tel: 01983 615 701 or 07922 12 34 16

Email: mam_nfm@yahoo.co.uk

Info, support and guidance - regular meetings, help with funding specialist equipment, team of trained visitors. Regional Care Development Advisers train volunteers - see Regional and Local Groups

Regional Contacts for IoW

<http://www.mndassociation.org/get-involved/volunteering/volunteer-zone/your-staff-contacts/staff-contacts-in-the-south-east-and-thames-valley/staff-contacts-isle-of-wight-branch/>

Claire Tuckett Volunteering Development Co-ordinator (VDC) Mob: 07831 349382

claire.tuckett@mndassociation.org

MULTIPLE SCLEROSIS

Website <http://www.wight-ms.org.uk>

Facebook <http://www.facebook.com/MS-Society-Isle-of-Wight-Branch-154416151364531/>

Support Lead Jenny Harrod isleofwightsupport@mssociety.org.uk Tel: 07976 629012 (text or voicemail only)

Secretary Livvy Kane isleofwight@mssociety.org.uk

Charity Shop Manager Helen Downer 01983 867500 mssocietyshanklin@gmail.com

Specialist Nurse Eileen Morley Tel: 01983 552094 /07917 558154 Elaine.Morey@iow.nhs.uk

MUSCULAR DYSTROPHY CAMPAIGN, Isle of Wight Branch

Contact: Mr Colin M Baker Tel: 01983 242961 Email: feathers455@hotmail.co.uk

www.muscular-dystrophy.org www.facebook.com/muscular dystrophycampaign

MYASTHENIA GRAVIS & OTHER MYASTHENIA CONDITIONS

Myaware Isle of Wight Support Group, (formerly Myasthenia Gravis Association, Isle of Wight)

contact Myaware, tel: 01332 290219, email: info@myaware.org , website: www.myaware.org

NHS Specialist nurse (Hants IOW, Dorset + Channel Islands)

Lisa Joyce: myasthenia@uhs.nhs.uk or Tel: 02381 205948

NEUROMUSCULAR DISEASES

This includes muscular dystrophy and many rare types such as Charcot Marie Tooth.

NHS Neuromuscular coordinator and Specialist Physiotherapist

Tel: 07798 667784 Email: Sunitha.narayan@uhs.nhs.uk

CMT- Hampshire Group Coordinator: Terry Dean Tel: 023 8055 9307 Email: terry@cmtuk.org.uk

PROGRESSIVE SUPRANUCLEAR PALSY

No local contacts, specific NHS service or 3rd sector group known to Neuro Network

SPINA BIFIDA

Isle of Wight Association for Spina Bifida and Hydrocephalus

Secretary: Ms Freya Conway Tel: 07535 004502 Email: littleowl2013@gmail.com

Chairman: Anne Axford Email: anneaxford@gmail.com

Contact through the website, by email or by telephone. Website: www.iwasbah.com

Facebook: <http://www.facebook.com/pages/Isle-of-Wight-Association-for-Spina-Bifida-and-Hydrocephalus/585664281508543>

STROKE Support Service Isle of Wight:

Stroke Recovery Service:

Mary Barton: 01983 898301 mary.barton@stroke.org.uk

Heidi Kurowska: 01983 898302 heidi.kurowska@stroke.org.uk

Stroke Recovery Service - Communication Support:

Tina Cutting: 01983 612729 tina.cutting@stroke.org.uk

Isle of Wight Stroke Club - Health conditions covered - Stroke - CVA, TIA

Contact: Tel: 01 983 869 100 Email: enquiries@wightfightingstroke.org

www.wightfightingstroke.org

www.facebook.com/home.php#!/groups/i.o.w.strokeclub/

(Also see Different Strokes above)

Additional Support for People with Neurological Conditions on IoW

AGE UK

01983 525282 www.ageukiw.org.uk

IAG, Lifeline project, Handyperson, small repairs - no charge for labour only materials, gardening service, Just About You - personal assistant service, nail cutting service, dementia services, falls prevention, digital inclusion, good neighbour scheme, active network of social groups.

CARERS IOW & QUAY CARERS

Health conditions covered - Unpaid Adult Carers of Adults. Contact: Elizabeth Martin Tel: 01983 533173 <http://carersiw.org.uk/>

JOHN CHEVERTON INFORMATION AND SUPPORT CENTRE

Earl Mountbatten Hospice, Halberry Lane, Newport, Isle of Wight PO30 2ER

<http://www.iwhospice.org/about-us.aspx> Email: infosupport@iwhospice.org

Tel: 01983 535320 or 01983 535319

The centre is open to anyone and everyone affected in anyway by any potentially life limiting illness (this includes relatives, friends, carers and health care professionals). It is open Monday to Friday 10am-4pm on a drop in basis and has been designed to offer contact, support, information, signposting, direction and help, advice and guidance café, listening, travel information, counselling services, benefits advice, employment & legal advice. Someone will always be available to listen to you and discuss your needs.

THE HEIGHTS LEISURE POOL

The Heights The Broadway Sandown Isle of Wight PO36 9ET Tel: 01983 405594

Open 7 Days a week - call first to confirm opening times. Have a hoist to assist swimmers who have additional needs.

INDEPENDENT LIVING CENTRE (ILC) - user led organisation

Downside Community and Learning Centre, Furlongs, Newport, IOW PO30 2AX

01983 241494 www.peoplematteriw.org www.riversidecentre.org.uk

Assessment of needs (self-referral or referred), OT on site - is able to assess more complex needs and advise appropriately. Includes a centre to demonstrate adaptations IOW based organisation supporting those with Long-term Neurological Conditions and Carers -

PARES (Personal Recruitment and Employment Service) helps to link suitable personal assistant to client. Client is in control of the interview process.

TAP (Team Around the Person) assessment - ensures everyone around the person e.g. carers, support workers, family & voluntary organisations work together to support you.

ISLE HELP HUB

Centre in Newport for contacting the following: Citizens Advice Bureau, People Matter, Footprint Trust, Age UK IOW, Law Society, Community Action Isle of Wight Tel: 01983 823898

<http://www.islefindit.org.uk> Advice Hub, 7 High Street, Newport, Isle of Wight, PO30 1SS

LOCAL AREA COORDINATORS

Active knowledgeable coordinators in different localities connecting vulnerable people to build their vision of a good life. <https://iwight.com/Residents/Care-Support-and-Housing/Community-Health-and-Wellbeing/Local-Area-Coordination/Introduction7/> or via IOW Council 01983 821000

SHOP MOBILITY

Tel: 01983 718950 Email: info@iowshopmobility.org.uk

Run by volunteers, it supplies a mobility scooter and wheelchair hire service so people can shop independently. It is located in Newport Town Centre, on the corner of South Street/Orchard Street, beside the Church Litten Car Park, near the library and bus station. Office Open Hours / Hire Times: Tue 10.00 – 3.30, Wed 10.30 – 2.30, Thu 10.30 – 2.30, Fri 10.00 – 3.30

WEST WIGHT SPORTS CENTRE

Moa Place, Freshwater, IOW PO40 9XH www.westwight.org.uk
provides exercise and Information

Special care swimming sessions on Wednesdays with hoist, warmer water and extra staff to support.

WIGHTCARE

Bugle House, 11a High Street, Newport PO30 1TP

01983 821105 wightcare@iow.gov.uk and www.iwight.com/wightcare

Round the clock reassurance, personal alarms, assisted technology and telecare work in partnership with Health and Social Care. Responders are trained in First Aid. Short term, long-term and holiday/respite installations

ISLE ACCESS

A one-stop location for visitors and Isle of Wight residents searching for information about access at places and venues around the Island. Our listings include recommendations on accommodation and links to the transport companies that serve the Isle of Wight. We also provide disability awareness training, customer advisory groups, advice on completing access statements and much more www.isleaccess.co.uk 07522 558 999

Adult Services Contacts

Hampshire, Isle of Wight, Portsmouth, Southampton & Neighbouring Local Authorities

Dorset County Council

- Social care information: [Community Care \(Adult Social Care\) Services](#)
- Dorset Adult Access Team: 01305 221016
- Bournemouth Care Direct: 01202 454979
- Poole Helpdesk: 01202 633902

Hampshire County Council

- Adult Social care <http://www3.hants.gov.uk/health>
- Adult Social Care: 0300 555 1386
- Out of hours / Emergency contact: 0300 555 1373
- Email: adult.services@hants.gov.uk

Isle of Wight Council

- Adult Social Care: 01983 823340
- Social care information: [Adult Social Care /](#)

Portsmouth City Council

- City Helpdesk: 023 9268 0810
- Out of hours / Emergency contact: 02392 822251
- Housing: [PCC Housing advice](#)
- Email: cityhelpdesk@portsmouthcc.gov.uk

Southampton City Council

- Adult Services: 023 8083 3003 from 8.30am- 5.00pm (Friday 4.30pm)
- Out of hours / Emergency contact: 023 8023 3344
- Website: www.southampton.gov.uk/health-social-care
- Housing: www.southampton.gov.uk/housing-council-tax

Surrey County Council

- Adult Services: 0300 200 1005. Alternatively use SMS: 07527 182861
- Out of Hours/ Emergency contact Tel: 01483 517898 or via text direct, 18001 01483 517898 Email: edt.ssd@surreycc.gov.uk
- Social care information: <http://www.surreycc.gov.uk/social-care-and-health>

West Berkshire Council

- Adult Services: 01635 503050
- Out of hours / Emergency contact: 01344 786543
- Social care information: <http://www.westberks.gov.uk/index.aspx?articleid=27090>

West Sussex County Council

- Adult Social: 01243 642121
- Social care information: <https://www.westsussex.gov.uk/social-care-and-health/how-to-get-social-care-help/adults/how-to-get-adult-social-care-help/>

Wiltshire County Council

- General Enquiries 0300 456 0111
- Out of hours / Emergency contact: 0300 456 0100
- Social care information: [Health and Social Care](#)
- customeradvisors@wiltshire.gov.uk

Wokingham Borough Council

- Adult Social Care (Optalis): 0118 974 6800
- Out of Hours / Social care emergencies: 01344 786 543
- Social care information: <http://www.wokingham.gov.uk/care-and-support-for-adults/>
- Email: wokinghamdirect@wokingham.gov.uk

Additional Support for People with Neurological Conditions and Carers

Carers Together

Phone: 01794 519495 admin@carerstogether.org.uk
<http://782186386632763965.weebly.com/> www.southamptoncarers.org.uk/

Elderly Advice Council and First Stop Care Advice

Tel: 0800 377 7070 www.housingcare.org/ www.firststopcareadvice.org.uk/

Hampshire Neurological Alliance

Tel: 07847 794937 contact@hampshireneural.org.uk www.hampshireneural.org.uk

Queen Elizabeth Foundation

QEF, Leatherhead Court, Woodlands Road, Leatherhead, Surrey KT22 0BN

Tel: 01372 841100

<http://qef.org.uk>, lists services that they offer.

British Red Cross

www.redcross.org.uk/ Tel: 0344 871 11 11

Macmillan

www.macmillan.org.uk/Home.aspx Tel: 0808 808 0000

Marie Curie

www.mariecurie.org.uk/ Tel: 0800 090 2309

Dying Matters

<http://dyingmatters.org/> Tel: Freephone 08000 21 44 66

There are many patient groups online where you can connect with others, who have similar neurological conditions.

These can be invaluable in terms of not feeling alone in what you are experiencing.

Patient.co.uk is one site where you can obtain health information and connect to others via the forums section. www.patient.co.uk/

Facebook also has a number of closed patient groups for different conditions. www.facebook.com/

