

## 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<br>Vestibular Schwannoma                         | British Acoustic Neuroma Association: <a href="http://www.bana-uk.com">www.bana-uk.com</a><br>Tel 0800 652 3143  |
| Alzheimer's   | Alzheimer's Society: <a href="http://www.alzheimers.org.uk">www.alzheimers.org.uk</a><br>Tel: 0300 222 1122  |
| Aphasia   | Connect: <a href="http://www.ukconnect.org">www.ukconnect.org</a> Tel 020 7367 0864  |
| Ataxia (including Friedrich's Ataxia)                             | Ataxia UK: <a href="http://www.ataxia.org.uk">www.ataxia.org.uk</a> Tel: 01582 760 733   |
| Ataxia-Telangiectasia<br>Louis-Bar Syndrome                       | Ataxia-Telangiectasia Society: <a href="http://www.atsociety.org.uk/">www.atsociety.org.uk/</a> Tel:<br>01582 760 733  |
| Autism  | The National Autistic Society <a href="http://www.autism.org.uk/">www.autism.org.uk/</a><br>Tel: 0808 800 4104 Lines are open 10am-4pm, Mon-Fri<br>(free from landlines & most mobiles)  |
| Bells Palsy   | <a href="http://www.bellspalsy.org.uk/">www.bellspalsy.org.uk/</a>   |
| Brain Aneurysm (unruptured)                                       | see subarachnoid haemorrhage   |
| Brain Haemorrhage   | see subarachnoid haemorrhage   |
| Brain Injury (Acquired)   | UK Acquired Brain Injury Forum: <a href="http://www.ukabif.org.uk">www.ukabif.org.uk</a><br>Tel 0845 608 0788  |
| Brain Tumour  | Brain Tumour UK: <a href="http://www.braintumouruk.org.uk">www.braintumouruk.org.uk</a><br>Tel 0808 800 004  |
| Cavernoma - Cerebral cavernous<br>malformations Cavernous angioma | Cavernoma Alliance UK: <a href="http://www.cavernoma.org.uk">www.cavernoma.org.uk</a><br>Tel 01305 213876  |
| Cerebral Palsy  | Scope: <a href="http://www.scope.org.uk/home">www.scope.org.uk/home</a><br>Tel 0808 800 3333   |
| Charcot Marie Tooth Disease                                       | CMT UK: <a href="http://www.cmt.org.uk/">www.cmt.org.uk/</a> Tel 0800_6526316  |
| Chronic Fatigue Syndrome:   | See ME   |
| Creutzfeldt-Jakob disease   | CJD Support Network: <a href="http://www.cjdsupport.net/">www.cjdsupport.net/</a> Tel 01630 673973   |
| Dementia  | Dementia UK: <a href="http://www.dementiauk.org">www.dementiauk.org</a> Tel: 020 7697 4160<br>Admiral Nurse please contact our helpline on: 0845 257 9406<br><a href="mailto:direct@dementiauk.org">direct@dementiauk.org</a>            |
| Devic's Disease   | <a href="http://www.devic.org.uk/index.html">www.devic.org.uk/index.html</a> Contact: <a href="mailto:info@devic.org.uk">info@devic.org.uk</a>   |
| Dysphasia   | Speakability: <a href="http://www.speakability.org.uk">www.speakability.org.uk</a> Tel: 080 8808 9572  |
| Dyspraxia   | Dyspraxia Foundation Tel: 01462 455 016<br>Email: <a href="mailto:dyspraxia@dyspraxiafoundation.org.uk">dyspraxia@dyspraxiafoundation.org.uk</a><br><a href="http://www.dyspraxiafoundation.org.uk/">www.dyspraxiafoundation.org.uk/</a> |

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| Dystonia  | The Dystonia Society: <a href="http://www.dystonia.org.uk">www.dystonia.org.uk</a><br>Tel 0845 458 6322  |
| Encephalitis  | The Encephalitis Society: <a href="http://www.encephalitis.info">www.encephalitis.info</a><br>Tel 01653 692583   |
| Epilepsy  | <ul style="list-style-type: none"> <li>Epilepsy Action: <a href="http://www.epilepsy.org.uk">www.epilepsy.org.uk</a><br/>Tel 0808 800 5050</li> <li>Epilepsy Society: <a href="http://www.epilepsysociety.org.uk">www.epilepsysociety.org.uk</a><br/>Tel 01494 601 300/ 400</li> </ul> |
| Essential tremor  | National Tremor Foundation: <a href="http://www.tremor.org.uk">www.tremor.org.uk</a><br>Tel 01708 386399   |
| Fibromyalgia  | Fibro Action: <a href="http://www.fibroaction.org">www.fibroaction.org</a> Tel 0844 443 5422   |
| Guillain Barré Syndrome   | Guillain Barré Syndrome Support Group:<br><a href="http://www.gaincharity.org.uk/">www.gaincharity.org.uk/</a> Tel 0800 374803   |
| Headway   | Headway: <a href="http://www.headway.org.uk">www.headway.org.uk</a><br>Tel 0800 800 2244   |
| Hemifacial Spasm  | <a href="http://www.patient.co.uk/health/hemifacial-spasm-leaflet">www.patient.co.uk/health/hemifacial-spasm-leaflet</a><br><a href="http://www.dystonia.org.uk">www.dystonia.org.uk</a> Helpline: 0845 458 6322   |
| Hemiparesis   | HemiHelp: <a href="http://www.hemihelp.org.uk">www.hemihelp.org.uk</a> Tel: 0845 123 2372  |
| Hereditary Sensori-Motor Neuropathies   | See Charcot Marie Tooth Disease  |
| Huntington's Disease  | Huntington's Disease Association: <a href="http://www.hda.org.uk">www.hda.org.uk</a><br>Tel 0151 331 5444  |
| Hydrocephalus   | See Spina Bifida   |
| Joubert Syndrome K  | Tel/Text: 07530 254743 <a href="http://www.jsuk.org/">www.jsuk.org/</a>  |
| Meniere's Disease   | Ménière's Society 0845 120 2975 <a href="http://www.menieres.org.uk">www.menieres.org.uk</a>   |
| Meningitis  | Meningitis Trust: <a href="http://www.meningitisnow.org/">www.meningitisnow.org/</a><br>Tel 0808 80 10 388   |
| Mental Health   | <ul style="list-style-type: none"> <li><a href="http://www.mind.org.uk/">www.mind.org.uk/</a></li> <li><a href="http://www.mentalhealth.org.uk/">www.mentalhealth.org.uk/</a></li> <li><a href="http://www.mentalhealthintheuk.co.uk/">www.mentalhealthintheuk.co.uk/</a></li> </ul>   |
| Migraine  | <ul style="list-style-type: none"> <li>Migraine Trust: <a href="http://www.migrainetrust.org">www.migrainetrust.org</a> Tel 020 7631 6970</li> <li>Migraine Action: <a href="http://www.migraine.org.uk">www.migraine.org.uk</a> Tel 0116 275 8317</li> </ul>                          |
| Motor Neurone Disease   | MNDA Association <a href="http://www.mndassociation.org/">www.mndassociation.org/</a><br>Tel 08457 626262  |
| Multiple Sclerosis (MS)   | MS Society <a href="http://www.mssociety.org.uk">www.mssociety.org.uk</a><br>Tel: 0808 800 8000 (free) Email: <a href="mailto:helpline@mssociety.org.uk">helpline@mssociety.org.uk</a>   |
| Multiple System Atrophy   | MSA Trust: <a href="http://www.msatrust.org.uk">www.msatrust.org.uk</a><br>Tel 020 7940 4666   |
| Muscular Dystrophy  | Muscular Dystrophy Campaign: <a href="http://www.muscular-dystrophy.org">www.muscular-dystrophy.org</a><br>Tel: 020 7803 4800  |
| Myalgic Encephalomyelitis<br>Myalgic Encephalopathy<br>ADEM (Acute Disseminated<br>Encephalomyelitis) | ME Association: <a href="http://www.meassociation.org.uk">www.meassociation.org.uk</a><br>Tel 01280 818968   |

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| Myasthenia Gravis and other Myasthenia Conditions | Myaware (formerly Myasthenia Gravis Association):<br>Tel: 01332 290219 Email: <a href="mailto:info@myaware.org">info@myaware.org</a><br>Website: <a href="http://www.myaware.org">www.myaware.org</a>  |
| Narcolepsy  | Narcolepsy UK <a href="http://www.narcolepsy.org.uk">www.narcolepsy.org.uk</a> Tel 0845 450 0394   |
| Neurofibromatosis                                 | The Neuro Foundation: <a href="http://www.nfauk.org">www.nfauk.org</a> Tel 020 8439 1234   |
| Pain and Pain Management                          | Pain UK <a href="http://www.painuk.org/">www.painuk.org/</a>   |
| Parkinson's Disease                               | Parkinson's UK: <a href="http://www.parkinsons.org.uk">www.parkinsons.org.uk</a><br>Tel 0808 800 0303  |
| Polio and Post-polio Syndrome                     | British Polio Fellowship: <a href="http://www.britishpolio.org.uk/">www.britishpolio.org.uk/</a><br>Tel 0800 018 0586  |
| Progressive Supranuclear Palsy                    | The PSP Association: <a href="http://www.pspeur.org">www.pspeur.org</a><br>Tel 0300 0110 122   |
| Raynaud's Syndrome                                | Raynaud's and Scleroderma Association<br><a href="http://www.raynauds.org.uk/">www.raynauds.org.uk/</a>  |
| Rett Syndrome                                     | Rett UK: <a href="http://www.rettuk.org">www.rettuk.org</a> Tel:01582 798 911  |
| Spina Bifida                                      | Spina bifida hydrocephalus Association: <a href="http://www.asbah.org">www.asbah.org</a><br>Now known as SHINE <a href="http://www.shinecharity.org.uk/">www.shinecharity.org.uk/</a><br>Tel 01733 555988  |
| Spinal Cord Injury                                | <ul style="list-style-type: none"> <li>• Aspire: <a href="http://www.aspire.org.uk">www.aspire.org.uk</a> Tel 020 8954 5759</li> <li>• Spinal Injuries Association: <a href="http://www.spinal.co.uk">www.spinal.co.uk</a><br/>Tel 0845 678 6633 or 01908 604 191</li> </ul> |
| Spinal Cord Injury                                | Spinal Injuries Association: <a href="http://www.spinal.co.uk">www.spinal.co.uk</a><br>Tel 0845 678 6633 or 01908 604 191  |
| Spinal Muscular Atrophy (SMA)                     | <a href="http://www.smatrust.org">www.smatrust.org</a>   |
| Spinal Tumour                                     | Brain and Spine Foundation: <a href="http://www.brainandspine.org.uk">www.brainandspine.org.uk</a><br>Tel 0808 808 1000  |
| Stroke  | The Stroke Association: <a href="http://www.stroke.org.uk">www.stroke.org.uk</a><br>Tel 0303 3033 100  |
| Subarachnoid Haemorrhage                          | Brain and Spine Foundation:<br>Tel 0808 808 1000 <a href="http://www.brainandspine.org.uk">www.brainandspine.org.uk</a>  |
| TIA   | See Stroke   |
| Tourettes Syndrome                                | Tourettes Action: <a href="http://www.tourettes-action.org.uk">www.tourettes-action.org.uk</a><br>Tel 0300 777 8427  |
| Transverse Myelitis                               | The Transverse Myelitis Society: <a href="http://www.myelitis.org.uk">www.myelitis.org.uk</a>  |
| Tremor  | National Tremor Foundation, Long Term Conditions Centre,<br>Gubbins Lane, Harold Wood, Essex RM3 0AR<br>Telephone: 01708 386399 Email: <a href="mailto:tremorfoundation@aol.com">tremorfoundation@aol.com</a>  |
| Trigeminal Neuralgia                              | Trigeminal Neuralgia Association UK.<br>Tel: 01883 370214 Email: <a href="mailto:help@tna.org.uk">help@tna.org.uk</a>  |
| Tuberous Sclerosis                                | Tuberous Sclerosis Association: <a href="http://www.tuberous-sclerosis.org">www.tuberous-sclerosis.org</a>   |
| Wilson's Disease                                  | Wilson's Disease Support Group UK<br><a href="http://www.wilsonsdisease.org.uk/WDSG-PO.asp">www.wilsonsdisease.org.uk/WDSG-PO.asp</a>  |

*‘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:** [wcw@alzheimers.org.uk](mailto:wcw@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](mailto:basingstoke-district@alzheimers.org.uk)
- Area:** New Forest & Southern Test Valley Office, Alzheimer's Society, War Memorial Hospital, Sea Road, Milford on Sea, Lymington, Hampshire SO41 0PG  
**Telephone:** 01590 644 679      **Email:** [jane.rowlatt@alzheimers.org.uk](mailto:jane.rowlatt@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](mailto: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](mailto:southampton@alzheimers.org.uk)
- Area:** Winchester Office, Alzheimer's Society, The Coach House, St Waleric Resource Centre, Park Road, Winchester SO23 7BE  
**Telephone:** 01962 865 585      **Email:** [winchester@alzheimers.org.uk](mailto:winchester@alzheimers.org.uk)

### APHASIA

**Connect:** [www.ukconnect.org](http://www.ukconnect.org) **Regional Group:** Christchurch Helen Mann Tel: 020 7367 0864  
Email: [helenmann@ukconnect.org](mailto: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: [Alan01morris@yahoo.co.uk](mailto:Alan01morris@yahoo.co.uk)

### AUTISM Hampshire

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

**Outreach Services** Information, Advice, Projects...

22 Midanbury Lane, Bitterne Park, Southampton, Hampshire, SO18 4HP

Tel: 02380 633951      Email: [outreach@autismhampshire.org.uk](mailto:outreach@autismhampshire.org.uk)

Outreach Department - Portsmouth Office Tel: 02392 814723

For more information on our Outreach Services 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](mailto: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      Email: [domcare@autismhampshire.org.uk](mailto:domcare@autismhampshire.org.uk)

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

### BRAIN TUMOUR

Brain Tumour Charity UK      [www.thebraintumourcharity.org/](http://www.thebraintumourcharity.org/)

Regional Group Hampshire and Surrounding Areas Operations Manager Rebecca Shortt (*note spelling*) [Contact Rebecca](#)

## **BRAIN AND SPINE**

Brain & Spine Foundation, 3.36 Canterbury Court, Kennington Park, 1-3 Brixton Road, London SW9 6DE Tel: 020 7793 5900 Email: [info@brainandspine.org.uk](mailto:info@brainandspine.org.uk) Helpline Tel 0808 808 1000

## **CEREBRAL PALSY**

Scope Winchester & District Hon. Sec. Shirley Kenneally [www.scope.org.uk/response](http://www.scope.org.uk/response)

## **CHARCOT MARIE TOOTH**

CMT United Kingdom, 98 Broadway, Southbourne, Bournemouth BH6 4EH  
Freephone: 0800 6526316 Tel: 01202 432048 Mobile: 07790 789008 [info@cmtuk.org.uk](mailto:info@cmtuk.org.uk)  
Hampshire Group Coordinator: Terry Dean 023 8055 9307 Email: [terry@cmtuk.org.uk](mailto:terry@cmtuk.org.uk)

## **CHRONIC FATIGUE** See ME

## **CORTICO BASAL DEGENERATION (CBD)**

Hampshire Contact Louise Roberts-West Tel: 07721 073 342  
Email: [jockandlouby@googlemail.com](mailto:jockandlouby@googlemail.com)

## **DYSPHASIA**

**Speakability (Action for Dysphasic Adults)** 240 City Road, London EC1V 2PR  
Tel: 020 7261 9572 Email: [speakability@speakability.org.uk](mailto:speakability@speakability.org.uk)  
**Information Service and Helpline:** Tel: 080 8808 9572 Tues to Thurs (11.00a.m - 3.00p.m)  
otherwise answerphone. In Hampshire there are local groups in Basingstoke and Ringwood.  
Please contact London office for more details.

## **DYSTONIA**

**Dystonia Society** 2nd Floor, 89 Albert Embankment, Vauxhall, London SE1 7TP  
Helpline: 020 7793 3650 Office: 020 7793 3651 Email: [info@dystonia.org](mailto:info@dystonia.org)  
Hampshire local group in Wickham, East Hants, run by volunteers.  
Contact Peter Cole 0845 899 7120. Email: [info@dystonia.org](mailto: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](http://www.encephalitis.info) contact 01653 692583 or email: [support@encephalitis.info](mailto: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/](http://www.epilepsysociety.org.uk/)  
**S.E. Regional Manager** Trevor Hutton Tel: 01273 441 401 Mobile: 07834 655992.  
Email [trevor.hutton@epilepsysociety.org.uk](mailto:trevor.hutton@epilepsysociety.org.uk)  
**Regional Services Coordinator** Judy Consden Tel 01494 601 300 switchboard or  
direct line 01494 601 389 Email [judy.consden@epilepsysociety.org.uk](mailto:judy.consden@epilepsysociety.org.uk)  
Epilepsy Society does not operate any support groups and does not have regional offices.  
NHS Epilepsy Nurses: [epilepsysupport@uhs.nhs.uk](mailto:epilepsysupport@uhs.nhs.uk)

## **HEADWAY**

**Headway UK** Network Support Coordinator Sue Gillard Tel: 07826 855811  
Headway National [www.headway.org.uk/home.aspx](http://www.headway.org.uk/home.aspx)  
**Headway Basingstoke** Headway House, Homefield Way, Basingstoke, Hampshire RG24 9SP  
Service Manager Heather Jury Tel: 01256 314969 Email: [hjury@headwaybasingstoke.org.uk](mailto:hjury@headwaybasingstoke.org.uk)  
**Headway Portsmouth and South East** Headway Portsmouth & South-East Hants, Mountbatten  
Centre, Grandstand Suite, Alexandra Park, Portsmouth, Hampshire PO2 9QA  
Service Manager Deborah Robinson Tel: 023 9266 4972  
Email: [info@headwayportsmouth.co.uk](mailto:info@headwayportsmouth.co.uk) Website: <http://headwayportsmouth.co.uk/>  
**Headway Isle of Wight** Joy Cleightonhills 01983 874651 [joy.headwayiow@gmail.com](mailto:joy.headwayiow@gmail.com)

## HEMIPLEGIA

Joanna Griffin, Home Visitor (SOUTHERN ENGLAND and Wales) - [joanna@hemihelp.org.uk](mailto:joanna@hemihelp.org.uk)

## HUNTINGTON'S DISEASE ASSOCIATION

Regional Care Advisor (Hants, Berks, IoW)

Eve Payler Tel: 023 8061 2218 Email: [eve.payler@hda.org.uk](mailto:eve.payler@hda.org.uk)

## M.E. ASSOCIATION

There are support groups in

**Andover** Email; [andoverfms.me.chatterbook@live.co.uk](mailto:andoverfms.me.chatterbook@live.co.uk)

**Eastleigh/ Winchester** Contact Kathleen McCall Email: [kathleenmccall@gmail.com](mailto:kathleenmccall@gmail.com)

Tel: 02380 251719 [www.eastwinme.ik.com/](http://www.eastwinme.ik.com/)

**Hampshire-wide including IoW** Email: [membership@hantsmesupport.co.uk](mailto:membership@hantsmesupport.co.uk)

Tel: 0845 834 0325 [www.meassociation.org.uk/2009/09/hampshire/](http://www.meassociation.org.uk/2009/09/hampshire/)

## MENINGITIS

Sonja Butler, Community Support Officer, SOUTH AND SOUTH EAST ENGLAND

[www.meningitisnow.org/how-we-help/local-support/south-and-south-east/](http://www.meningitisnow.org/how-we-help/local-support/south-and-south-east/)

Call Sonja on 0845 340 2454 or Email: [sonjab@meningitis-trust.org](mailto:sonjab@meningitis-trust.org) to arrange a home visit or to talk about how we can help you.

## MOTOR NEURONE DISEASE Telephone: 01604 250505

**Hants, Dorset, IoW, Channel Isles South Central**

**Regional Officer** - Louise Rickenbach Email: [louise.rickenbach@mndassociation.org](mailto:louise.rickenbach@mndassociation.org)

Tel: 0845 375 1831 MND Connect 08457 626262

**Local support groups**

**Southampton / Winchester** Contact [Mrs\\_rocket@hotmail.com](mailto:Mrs_rocket@hotmail.com) Tel 023 8089 1842

**Basingstoke** Contact: [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org) Tel 08457 626262

**Portsmouth** Contact: [andrew.lane72@sky.com](mailto:andrew.lane72@sky.com) Tel 01489 790978

## MULTIPLE SCLEROSIS

**Service Development Officer - Hants and IoW MS Society** Karen Tucker Tel: 020 8438 0742

Mobile: 07901 521616 Switchboard: 020 8438 0700 Email: [Karen.Tucker@mssociety.org.uk](mailto:Karen.Tucker@mssociety.org.uk)

Web: [www.mssociety.org.uk](http://www.mssociety.org.uk) **NHS MS coordinator** in Southampton is [sarah.gibbs2@uhs.nhs.uk](mailto: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.

## MULTIPLE SYSTEM ATROPHY

There are local groups in

**Dorset** Contact [sue@pinfield-wells.com](mailto:sue@pinfield-wells.com) Tel 020 7940 4666

**Reading** Contact Sue Ryder - Duchess of Kent House Tel 0118 9550 4001

**Dorset** Contact Lewis Manning Hospice Tel: 01202 708 470

**Wokingham Berks**, Contact Howard Clinic Tel 0118 989 7502

**Wiltshire** Contact [office@msatrust.org.uk](mailto:office@msatrust.org.uk) Tel 020 7940 4666

## 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.muscular-dystrophy.org/how_we_help_you/care_and_support)

Also at Muscular Dystrophy Campaign Tel 020 7803 4800 Email: [info@muscular-dystrophy.org](mailto:info@muscular-dystrophy.org)

## MYASTHENIA GRAVIS AND OTHER MYASTHENIA CONDITIONS now MYAWARE

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

Tel: 01332 290219 Email: [info@myaware.org](mailto:info@myaware.org) Website: [www.myaware.org/about-myaware](http://www.myaware.org/about-myaware)

**Myaware Hampshire Branch** Contact: [www.mga-hants.finneys.me.uk/](http://www.mga-hants.finneys.me.uk/)

**Myaware Isle of Wight**

Contact: Lynne Picher Tel: 01983 761265 Email: [piglettina@btopenworld.com](mailto:piglettina@btopenworld.com)

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

Lisa Joyce Email: [myasthenia@uhs.nhs.uk](mailto:myasthenia@uhs.nhs.uk)

## NEUROFIBROMATOSIS

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](http://www.nfauk.org/about-us/specialist-advisors)

## PARKINSONS South Region

Buckinghamshire, Oxfordshire, Berkshire, Hampshire And The Isle Of Wight.

Abbi Hayden - Information and Support Manager

Tel: 0844 225 3672 Email: [ism.south@parkinsons.org.uk](mailto:ism.south@parkinsons.org.uk) -

[www.parkinsons.org.uk/content/our-work-south-england](http://www.parkinsons.org.uk/content/our-work-south-england)

[www.parkinsons.org.uk/content/our-work-south-england#sthash.cKhdQgsG.dpuf](http://www.parkinsons.org.uk/content/our-work-south-england#sthash.cKhdQgsG.dpuf)

There are local groups for all ages and younger people's groups in some areas

local groups link: [www.parkinsons.org.uk/isw/regions/south-of-england](http://www.parkinsons.org.uk/isw/regions/south-of-england)

## SPINA BIFIDA

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

Telephone: 01959 534618 E-mail: [contact@shinecharity.org.uk](mailto:contact@shinecharity.org.uk)

Naomi Marston Regional Development Manager Telephone: 01959 534618

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

**Southampton and District Association for Spina Bifida and Hydrocephalus**

Contact: Stan Fitzgerald (Chair) Email: [chairman@sdsbha.org.uk](mailto:chairman@sdsbha.org.uk) Tel: 02380 402644

Fiona Trevett (Secretary) Email: [secretary@sdsbha.org.uk](mailto:secretary@sdsbha.org.uk) Tel: 02380 448466

Website: [www.sdsbha.org.uk](http://www.sdsbha.org.uk)

**Spinal Cord Injuries Spinal Injuries Association (SIA) South**

Peer Support Steve on 07535 590510 or email him at [s.hodges@spinal.co.uk](mailto:s.hodges@spinal.co.uk)

Outreach Team [www.spinal.co.uk/page/outreach-team](http://www.spinal.co.uk/page/outreach-team)

## STROKE

**Stroke Association, Area Manager, South Central**

Esme Mutter Tel: 023 80720426 or Email: [esme.mutter@stroke.org.uk](mailto:esme.mutter@stroke.org.uk)

The Stroke Association's service support across Hampshire is for Communication Support as follows:

|                                      |                |              |  |
|--------------------------------------|----------------|--------------|--|
| New Forest:                          | Yvonne Hobbs   | 01425 275139 | <a href="mailto:yvonne.hobbs@stroke.org.uk">yvonne.hobbs@stroke.org.uk</a>     |
| West Hants:                          | John Shaw      | 01256 471301 | <a href="mailto:john.shaw@stroke.org.uk">john.shaw@stroke.org.uk</a>           |
| Central Hants:                       | Rachel Davies  | 01256 471301 | <a href="mailto:rachel.davies@stroke.org.uk">rachel.davies@stroke.org.uk</a>   |
| North East Hants:                    | Sam Malkin     | 01256 471301 | <a href="mailto:sam.malkin@stroke.org.uk">sam.malkin@stroke.org.uk</a>         |
| South East Hants:                    | Mandy Souter   | 01730 233998 | <a href="mailto:mandy.souter@stroke.org.uk">mandy.souter@stroke.org.uk</a>     |
| Fareham, Gosport<br>and Portsmouth:  | Gillian Norrie | 07717 275850 | <a href="mailto:gillian.norrie@stroke.org.uk">gillian.norrie@stroke.org.uk</a> |
| Southampton and<br>surrounding area: | Suzie Maidment | 02380 562011 | <a href="mailto:suzie.maidment@stroke.org.uk">suzie.maidment@stroke.org.uk</a> |

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](http://www.stroke.org.uk/support/search)

For services on the Isle of Wight please see page 68

## TOURETTES

Dorset, Surrey, Sussex, Hampshire, IoW Email: [emma@tourettes-action.org.uk](mailto:emma@tourettes-action.org.uk)

Southampton group and Portsmouth group both meet regularly. A new IoW group has started.



## Isle of Wight Support Organisations

### ACQUIRED BRAIN INJURY

Headway IoW Local branch Joy Cleightonhills 01983 874651 [hiowsecretary@gmail.com](mailto:hiowsecretary@gmail.com)  
NHS Specialist nurse in Southampton is [Miranda.Gardner@uhs.nhs.uk](mailto: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](mailto: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](mailto:alzheimercafeiow@btconnect.com)  
[www.alzheimercafeiow.org.uk](http://www.alzheimercafeiow.org.uk) Facebook – AlzheimerCafeIOW Twitter - @AzCafeIOW

ATAXIA IOW Support Group Alan Reed 01983 867946 Email: [punkyal@hotmail.co.uk](mailto:punkyal@hotmail.co.uk)

### AUTISM INCLUSION MATTERS (AIM) GROUP

Tel: 01983 523000 - ask to speak to the AIM coordinator. Email: [aimisleofwight@gmail.com](mailto: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.

CHARCOT MARIE TOOTH - see Neuromuscular Diseases

### DIFFERENT STROKES, Isle of Wight

Contact: Sue Preater Tel: 01983 533236 Email: [isleofwight@differentstrokes.co.uk](mailto: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: [davidpiggott@yahoo.co.uk](mailto:davidpiggott@yahoo.co.uk)  
Patients with Epilepsy and families are welcomed by the Headway group even without a brain injury causing their epilepsy. Patients with LD are supported by Lesley Mew, LD nurse

### FIBROMYALGIA

Self-help support group meets in Ryde. Contact: Karen Smith Tel: 0844 887 2346  
Email: [iwfmsq.fibromates@gmail.com](mailto:iwfmsq.fibromates@gmail.com) [www.isleofwightfibromyalgia.webs.com](http://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  
Joy Cleightonhills: 01983 874651 Email: [hiowsecretary@gmail.com](mailto:hiowsecretary@gmail.com)

### HUNTINGTONS

Regional Care Advisor (Hants, Berks, IOW) [eve.payler@hda.org.uk](mailto:eve.payler@hda.org.uk) or  
[a.scivier@btinternet.com](mailto:a.scivier@btinternet.com) Several IOW families meet with Hampshire Branch

## **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](mailto:mam_nfm@yahoo.co.uk) Local Branch Website: [www.mndiw.btck.co.uk](http://www.mndiw.btck.co.uk)

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

## **MULTIPLE SCLEROSIS**

Specialist Nurse 01983 552094 /07917 558154 [Elaine.Morey@iow.nhs.uk](mailto:Elaine.Morey@iow.nhs.uk)

Local MS society [www.wight-MS.org.uk](http://www.wight-MS.org.uk) - see for local info

Contact: Jane Dollery Tel: 07976 629012 Email: [janeanniw@gmail.com](mailto:janeanniw@gmail.com)

## **MUSCULAR DYSTROPHY CAMPAIGN, Isle of Wight Branch**

Contact: Mr Colin M Baker Tel: 01983 242961 Email: [feathers455@hotmail.co.uk](mailto:feathers455@hotmail.co.uk)

[www.muscular-dystrophy.org](http://www.muscular-dystrophy.org) [www.facebook.com/muscular dystrophycampaign](http://www.facebook.com/muscular dystrophycampaign)

## **MYASTHENIA GRAVIS & OTHER MYASTHENIA CONDITIONS**

Myaware, Isle of Wight, (Formerly Myasthenia Gravis Association, Isle of Wight)

Contact Lynne Pitcher Tel: 01983 761265 Email: [piglettina@btopenworld.com](mailto:piglettina@btopenworld.com)

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

Lisa Joyce: [myasthenia@uhs.nhs.uk](mailto:myasthenia@uhs.nhs.uk) or Tel: 02380 795948

## **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](mailto:Sunitha.narayan@uhs.nhs.uk)

CMT- Hampshire Group Coordinator: Terry Dean Tel: 023 8055 9307 Email: [terry@cmtuk.org.uk](mailto:terry@cmtuk.org.uk)

## **PARKINSONS South Region**

Buckinghamshire, Oxfordshire, Berkshire, Hampshire and the Isle of Wight.

Abbi Hayden - Information and Support Manager

Tel: 0844 225 3672 Email: [ism.south@parkinsons.org.uk](mailto:ism.south@parkinsons.org.uk)

Regional information: [www.parkinsons.org.uk/content/our-work-south-england](http://www.parkinsons.org.uk/content/our-work-south-england)

Local information/support: [www.parkinsons.org.uk/isw/regions/south-of-england](http://www.parkinsons.org.uk/isw/regions/south-of-england)

Local groups for all ages and younger people's groups in some areas - local group link:

[www.parkinsons.org.uk/local-support-groups/regions/south-of-england](http://www.parkinsons.org.uk/local-support-groups/regions/south-of-england)

Parkinson's UK, IOW Branch Meetings take place around the Island. Other activities include exercise classes, curling and bowls, an art and social group and hydrotherapy sessions

Contact: Mr Ron Tweedie Tel: 01983 884913 Email: [rtweedie750@gmail.com](mailto:rtweedie750@gmail.com)

Rosemary Smith, Information Support Worker, Parkinsons UK

Tel: 08442 253678 or 020 7931 8080 Email: [rsmith@parkinsons.org.uk](mailto:rsmith@parkinsons.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: Mrs Cathy Clark Tel: 01983 209509 Email: [cathyclark13@hotmail.co.uk](mailto:cathyclark13@hotmail.co.uk)

Chairman: Adrian Axford Email: [adrian.axford@gmail.com](mailto:adrian.axford@gmail.com)

Contact through the website, by email or by telephone. Website: [www.iwasbah.com](http://www.iwasbah.com)

Chalet Secretary: Anne Axford Tel: 01983 562454 Email: [anneaxford@gmail.com](mailto:anneaxford@gmail.com)

## **STROKE Support Service Isle of Wight:**

Information, Advice & Support:

Mary Barton: 01983 898301 [mary.barton@stroke.org.uk](mailto:mary.barton@stroke.org.uk) and

Maeve Fuller: 01983 898302 [maeve.fuller@stroke.org.uk](mailto:maeve.fuller@stroke.org.uk)

Communication Support Tina Cutting: 01983 612729 [tina.cutting@stroke.org.uk](mailto:tina.cutting@stroke.org.uk)

Isle of Wight Stroke Club - Health conditions covered - Stroke - CVA, TIA  
Contact: Carole Greenham or Bob Stringer Tel: 01 983 869 100  
Email: [enquiries@wightfightingstroke.org](mailto:enquiries@wightfightingstroke.org) [www.wightfightingstroke.org](http://www.wightfightingstroke.org)  
[www.facebook.com/home.php#!/groups/i.o.w.strokeclub/](https://www.facebook.com/home.php#!/groups/i.o.w.strokeclub/)  
(Also see Different Stokes above)

## **Additional Support for People with Neurological Conditions on IoW**

### **AGE UK**

01983 525282 [www.ageukiw.org.uk](http://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 IW & QUAY CARERS**

Health conditions covered - Unpaid Adult Carers of Adults. Contact: Elizabeth Martin/Soo Scott  
Tel: 01983 533173 Email: [carersiw@btconnect.com](mailto:carersiw@btconnect.com) <http://carersukiwbranch.wordpress.com>

### **JOHN CHEVERTON INFORMATION AND SUPPORT CENTRE**

Earl Mountbatten Hospice, Halberry Lane, Newport, Isle of Wight PO30 2ER  
Tel: 01983 535320 or 01983 535319 Email: [infosupport@iwhospice.org](mailto:infosupport@iwhospice.org)  
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.

### **HELP AND CARE**

The Telephone Support Service provides advice, information and support to people with long term health conditions and their carers. Trained volunteers will telephone an individual between 6 - 10 times to have a chat to identify their needs and help them access the support and information available to them. This could range from information about local support groups, through to health fact sheets depending on what the individual requires.  
Tel: 01983 522609 Email: [iwinfo@helpandcare.org.uk](mailto:iwinfo@helpandcare.org.uk) [www.helpandcare.org.uk/isleofwight](http://www.helpandcare.org.uk/isleofwight)

### **INDEPENDENT LIVING CENTRE (ILC) - user led organisation**

Downside Community and Learning Centre, Furlongs, Newport, IOW PO30 2AX  
01983 241494 [www.peoplematteriw.org](http://www.peoplematteriw.org) [www.riversidecentre.org.uk](http://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

### **MEDINA LEISURE 01983 523767**

**ROYAL VOLUNTARY SERVICE (RVS) IOW**

Meals on wheels      Tel: 01983 524021      [www.royalvoluntaryservice.org.uk](http://www.royalvoluntaryservice.org.uk)

**SHOP MOBILITY**

Tel: 01983 718950      Email: [info@iowshopmobility.org.uk](mailto:info@iowshopmobility.org.uk)      [www.iowshopmobility.org.uk](http://www.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.co.uk](http://www.westwight.co.uk)

provides exercise and Information about self-management via a series of talks entitled “Living with Long Term Conditions”      [www.westwight.co.uk](http://www.westwight.co.uk)

Special care swimming sessions on Wednesdays

**WIGHTCARE**

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

01983 821105      [wightcare@iow.gov.uk](mailto:wightcare@iow.gov.uk) and [www.iwight.com/wightcare](http://www.iwight.com/wightcare)

Round the clock reassurance personal alarms assisted technology and telecare work in partnership with Health and Social care responders re trained in First Aid Short term long term and holiday/respite installations

## **Adult Services Contacts Hampshire, Isle of Wight, Portsmouth, Southampton & Neighbouring Local Authorities**

### **Dorset County Council**

- Social care information: [Community Care \(Adult Social Care\) Services](#)

### **Hampshire County Council**

- Adult Social Care: 0845 603 5630
- Out of hours / Emergency contact: 0845 600 45 55
- Email: [adult.services@hants.gov.uk](mailto: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](mailto: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](http://www.southampton.gov.uk/health-social-care)
- Housing: [www.southampton.gov.uk/housing-council-tax](http://www.southampton.gov.uk/housing-council-tax)

### **Surrey County Council**

- Adult Services: 0300 200 1005 - All calls including learning disabilities, occupational therapy and out of hours / emergency contact
- Social care information: [People and Community](#)

### **West Berkshire Council**

- Adult Services: 01635 503050
- Out of hours / Emergency contact: 01344 786543
- Social care information: [Adult social care - adult services](#)

### **West Sussex County Council**

- General enquiries: 01243 777100
- Social care information: [Adults looking for support](#)

### **Wiltshire County Council**

- Out of hours / Emergency contact: 0845 60 70 888
- Social care information: [Health and Social Care](#)
- Email: [socialcarehelpdesk@wiltshire.gov.uk](mailto:socialcarehelpdesk@wiltshire.gov.uk)

### **Wokingham Borough Council**

- Adult Social Care (Optalis): 0118 974 6832
- Telephone: 0118 974 6000
- Text: 07786 200 974
- Fax: 0118 978 9078
- Email: [wokinghamdirect@wokingham.gov.uk](mailto:wokinghamdirect@wokingham.gov.uk)
- Social Care Information: [Optalis](#)

## Additional Support for People with Neurological Conditions and Carers

### Carers Together

Phone: 01794 519495 [admin@carerstogether.org.uk](mailto:admin@carerstogether.org.uk)  
[www.carerstogether.org.uk/workers.php](http://www.carerstogether.org.uk/workers.php) [www.southamptoncarers.org.uk/](http://www.southamptoncarers.org.uk/)

### Elderly Advice Council and First Stop Care Advice

Tel: 0800 377 7070 [www.housingcare.org/](http://www.housingcare.org/) [www.firststopcareadvice.org.uk/](http://www.firststopcareadvice.org.uk/)

### Hampshire Neurological Alliance

Tel: 07847 794937 [contact@hampshireneural.org.uk](mailto:contact@hampshireneural.org.uk) [www.hampshireneural.org.uk](http://www.hampshireneural.org.uk)

### Queen Elizabeth Foundation

QEF, 1 Metcalfe Avenue, Carshalton, Surrey, SM5 4AW Tel: 020 8770 1151  
<http://qef.org.uk>, lists services that they offer.

### British Red Cross

[www.redcross.org.uk/](http://www.redcross.org.uk/) Tel: 0845 0547 222

### Macmillan

[www.macmillan.org.uk/Home.aspx](http://www.macmillan.org.uk/Home.aspx) Tel: 0808 808 0000

### Marie Curie

[www.mariecurie.org.uk/](http://www.mariecurie.org.uk/) Tel: 0800 716 146

### 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. Facebook also has a number of closed patient groups for different conditions.

[www.patient.co.uk/](http://www.patient.co.uk/)

[www.facebook.com/](http://www.facebook.com/)