

Sources of Funding, Information & Support

The Transverse Myelitis Society refers its members to other organisations when it does not offer the service a member may require. To aid that, this document provides information about alternative sources of funding, information and support. This document is in no way complete and you may know of an organisation and information that could be listed here. If you do, please send it to us at info@myelitis.org.uk.

The organisations are listed by need. You will see organisations that can meet more than one need so be sure to check the entire document.

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Ageing & Elderly

The following organisations provide information, support and/or funding for the elderly.

Age UK - <http://www.ageuk.org.uk>

- Age UK provide a range of information and advice about a wide range of matters of relevance to the elderly.

Cinnamons Trust - www.cinnamon.org.uk

Supports the elderly and terminally ill with caring for their pets.

Elderly Accommodation Counsel (EAC) - www.eac.org.uk

- The Elderly Accommodation Counsel (EAC) is a national charity that aims to help older people make informed choices about their housing and care needs.

Jigsaw Bury (Bury, Lancashire) – www.jigsawbury.org.uk.gridhosted.co.uk

- Jigsaw Bury is a Bury based registered charity. Jigsaw Link provides a one to one befriending service for people over the age of 50 who are disabled, or have an age related condition, and live in the Borough of Bury. We also offer a weekly luncheon club and social outings throughout the year as well as an Older People's Active Living Programme.

Benefits & Statutory Services

The following contains information on benefits and statutory services. This information is relevant to residents of the UK only.

The information portal for all public services in the UK including benefits, money advice and statutory services is via www.gov.uk

Access to Work - www.gov.uk/access-to-work/overview

- An Access to Work grant helps pay for practical support if you have a disability, health or mental health condition so you can start working, stay in work or start your own business. How much you get depends on your circumstances. The money doesn't have to be paid back and will not affect your other benefits. Access to Work is only available in England, Scotland and Wales.

Blue Badge – See under 'Driving & Transport'

Free bus pass – See under 'Driving & Transport'

Motability – See under 'Driving & Transport'

Personal Independence Payment - www.gov.uk/pip/overview

- All information relating to the Personal Independence Payment (PIP), which helps with some of the extra costs caused by long-term ill-health or a disability if you're aged 16 to 64. It provides an overview, what you can get, who is eligible, how to claim and making an appeal.
- The rate of what you get depends on how your condition affects you, not the condition itself. You will need an assessment to work out the level of help you can get and your award will be regularly assessed to make sure you are getting the right support.

Health & Social Care in Northern Ireland - www.hscni.net

- Information for health and social care services in Northern Ireland

NHS Choices – www.nhs.uk

- Main portal of information on services from the NHS

NHS Direct - www.nhsdirect.nhs.uk

- Gives health information and advice. Available 24 hours a day and 365 days a year

NHS Direct Wales - www.nhsdirect.wales.nhs.uk

- Gives health information and advice to people in Wales. Available 24 hours a day and 365 days a year

Carers

The following organisations provide information and support to carers.

Carers Direct (NHS) - www.nhs.uk/carersdirect/Pages/CarersDirectHome.aspx

- Information, advice and support for carers.
- 0808 802 0202

Carers Trust - www.carers.org

- Together with our Network Partners, we provide access to desperately-needed breaks, information and advice, education, training and employment opportunities. Our Network Partners benefit from the provision of grants, advice documents and reports to improve carers' services. We give carers and young carers avenues to speak to someone and make their voices heard, offline via our carers' services and young carers' schemes and online via our interactive websites.
- 0844 800 4361

Carers UK – www.carersuk.org

- Carers UK provides help, support and advice to carers, connect carers with other carers, and campaign for change.
- 0808 808 7777

Children & Young People

The following organisations provide information, support and/or grants for children and young people.

Action for Kids – www.actionforkids.org

- A national charity working with children and young people with physical and learning disabilities and their parents and carers. They help disabled children, young people, their parents and carers in three main ways: by providing mobility aids, work related learning and by offering family support services.

Aspire – www.aspire.org.uk

- Aspire offers practical support to people living with a spinal cord injury in the UK so that they can lead fulfilled and independent lives in their homes, with their families, in work places and in leisure time.
- They give funds to people to help them buy the specialist equipment they need to live a more independent life.
- Provide services to patients in the Spinal Cord Injury Centres ensuring they get the support and services they need and have independent access to a computer. They also provide accessible properties around the UK that can be used on a short-term basis whilst someone is adapting their own property or hunting for a permanent home.

Backup Trust - www.backuptrust.org.uk

- Our services include mentoring for families, wheelchair skills training and activity courses as well as support in getting back to work or school after an injury. All our services help to build confidence and independence. For information on services specifically for children, click here <http://www.backuptrust.org.uk/schoolsandfamilyinclusionservice>

Contact A Family - www.cafamily.org.uk

- Charity that supports parents with disabled children

Caudwell Children Trust – www.caudwellchildren.com

- Caudwell Children is a national Charity that exists to transform the lives of disabled children and their families across the UK. Applicants must live in the UK, be 18 or under and fit the Charity's financial criteria. They can provide the following equipment: powered wheelchairs, buggies, car seats, therapy tricycles and sensory equipment. In addition they can provide funding for specific therapies for children affected by CP/acquired brain injury and Autism. Caudwell Children's Enable Sport Programme provides sports equipment to enable disabled children to take part in competitive sport and their Destination Dreams holiday to Florida is an annual fully-supported group holiday for children fighting a life-threatening condition. The Charity can also offer fundraising support for some treatment abroad and they have also launched a family service programme in selected regions which provides practical and emotional support for families. For further information please contact 0845 300 1348.

Cerebra - www.cerebra.org.uk

- Cerebra grants are to help children (aged 16 or younger) who have disabilities because of a brain related condition or injury. The condition may be of a physical nature, a learning disability or both. Cerebra offer direct and practical assistance to improve the quality of life of children and young people, e.g. sensory toys, tricycles and quadricycles and touch screen computers. Applications must be supported by two references, one of which must be from a medical professional. Grants are paid to suppliers, not directly to the child/family.

Children Today Charitable Trust - www.childrentoday.org.uk

- Children Today raises funds to provide special equipment for children and young people with disabilities throughout the UK. Their aim is to ensure that every disabled child and young person fulfils their potential and leads an active childhood. Funds donated by their supporters enables them to provide grants to purchase special equipment such as: electric wheelchairs, walking aids, trikes, educational toys (specially designed for children with disabilities), communication aids, adapted car seats, lifting and sleep equipment.

Elifar – www.elifarfoundation.org.uk

- Elifar aims to help improve the quality of life mainly of profoundly disabled children and young adults, whether living at home or in residential care, but they might also consider applications from children and adults of all ages with any form of physical or learning disability. They fund the purchase of a wide range of specialised equipment, therapies and respite, which would otherwise be unavailable because of a lack of funds or because there is no statutory provision.

Family Action – www.family-action.org.uk

- Family Action has small grants available for medical treatment, services, facilities or equipment (including communication aids) for those who are sick or physically disabled. Supporting evidence is required from a relevant professional. There is also a general grants program which can meet needs such as clothing, fuel bills and household needs such as beds, cookers and washing machines. In addition to providing general grants, Family Action also provide grants for educational needs, particularly for the additional costs associated with education such as travel, books and equipment. Assistance is primarily targeted at families and individuals on low incomes, particularly those living on benefits. Funds are not available for items covered by statutory funding.

Family Fund - www.familyfund.org.uk

- The UK's largest provider of grants to low-income families raising disabled and seriously ill children and young people. We help ease the additional pressures families face. We can help with essential items such as washing machines, fridges and clothing but can also consider grants for sensory toys, computers and much needed family breaks together.

Get Kids Going – www.getkidsgoing.com

- Focuses on helping disabled young athletes and providing manual wheelchairs for children to use every day; at home, at school, and to enable them to play with their friends

Home Start - www.home-start.org.uk

- Home-Start is a national family support charity that supports parents as they learn to cope, improve their confidence and build better lives for their children. Our volunteers visit the family's home for a couple of hours every week. They tailor-make their support to the needs of the parents and children. Volunteers are very committed and will keep visiting until the youngest child turns five or starts school, or until the parents feel they can stand on their own two feet.

Independence at Home - www.independenceathome.org.uk

- Independence at Home provide grants for people with a disability or long-term illness towards the cost of adaptations, equipment or other things to help you to manage at home. The grant must go towards an item to assist a child to live at home. Independence at home cannot provide grants when the item

may be provided through public funds. Applications must be supported by a professional involved in the child's care, usually an occupational therapist or a social worker.

Jigsaw Bury (Bury, Lancashire) – www.jigsawbury.org.uk.gridhosted.co.uk

- Jigsaw Bury is a Bury based registered charity. Jigsaw is a sports and social group for young disabled people, based in Bury. Our aims are to promote fun, freedom and independence; support people to enjoy an active social life, help people reach their sporting potential and maintain a healthy lifestyle.

Lifeline 4 Kids – www.lifeline4kids.org

- Lifeline 4 kids provides essential equipment to help improve the quality of life for children (0-18 years) with disabilities and special needs. For the individual child they provide the full spectrum of specialised equipment such as electric wheelchairs, mobility aids and varying items including specialised computers. They are also one of the only UK charities prepared to help a special needs child from a low-income family with essential smaller items such as shoes, clothing, bedding and specialist toys.

Newlife Foundation for Disabled Children – www.newlifecharity.co.uk

- Newlife provides grants for equipment for disabled children. The equipment applied for must be essential and disability relevant. The equipment can vary from a wheelchair or a bed through to a communication aid and therapy equipment shed, they have also funded equipment such as replacement clothing and braille machines. Newlife do not fund adaptations and fixtures to homes. All applications need to be supported by professionals who can specify the particular type of equipment needed in the interest of the children's welfare, safety and benefit. The grants are open to benefit all seriously disabled and terminally ill children that are permanently resident in the UK and who are 18 years or under. Newlife don't means test, but due to limited funds they do take a view of the whole circumstances of the family.

Tree of Hope - www.treeofhope.org.uk

- The Tree of Hope offers hope to the families of sick children in the UK who need specialist medical surgery, treatment, therapy and equipment in order to free them from suffering, giving a better quality to their young lives.

The ACT Foundation - www.theactfoundation.co.uk

- ACT's grants generally fall into the following areas: building (funding modifications such as stairlifts, bathroom adaptations and vehicle adaptations), equipment (provision of specialised wheelchairs, other mobility aids and equipment including medical equipment to assist independent living) and financial assistance towards the cost of respite breaks. They will not make grants which would replace statutory funding and/or which would pay for work that has already taken place or equipment already purchased or on order.

Lord's Taverners - www.lordstaverners.org

- The Lord's Taverners is the UK's leading youth cricket and disability sports charity dedicated to giving disadvantaged and disabled young people a sporting chance. Our sporting roots are within cricket, but we also enjoy relationships with a wide range of other sports including rugby, tennis, squash, basketball and boccia.

Variety Club, The Children's Charity - www.varietyclub.org.uk

- The Variety Club works to help improve the lives of sick, disabled and disadvantaged children and young people up to the age of 19 years across the UK, providing basic items that will improve the lives of individual children. Each year they donate electric wheelchairs, specialist beds, car seats, sensory equipment, standing frames and many other items that can change the life of a child in need.

Whizz Kidz - <http://www.whizz-kidz.org.uk/>

- Support disabled children across the UK to become confident and independent young adults. They provide a parents' network, runs youth groups, wheelchair skills training, work placements and residential camps for young disabled people. Whizz-Kidz also provides mobility equipment - powered or manual wheelchairs and recreational equipment such as trikes - that are customised to meet individual children's needs.

Clothing

The following organisations provide information on accessing clothing.

Clothing Solutions - www.clothingsolutions.org.uk

- Clothing Solutions aim to offer clothing advice and information for all types of clothing problems.

Communication Aids

The following organisations provide information and support to people who require communication aids.

Arcos - www.arcos.org.uk

- ARCOS exists to promote and provide information, advice and support for people with communication and/or swallowing problems. They have an established library of equipment that they can consider to provide on trial or loan.

The Sequal Trust - www.thesequaltrust.org.uk

- Supports individuals to raise funds to obtain communication aids.

Communication Matters - www.communicationmatters.org.uk

- Communication Matters is a charitable organisation which is involved in a range of activities to support people to access the most appropriate communication aid.

Computer Access

The following organisations provide information on accessing and using computers and digital technology.

AbilityNet - www.abilitynet.org.uk

- AbilityNet exists to change the lives of disabled people by helping them to use digital technology at work, at home or in education.

Driving & Transport

The following organisations provide information on driving when you have a medical condition and/or disability.

Blue Badge – www.gov.uk/government/collections/blue-badge-scheme

- The Blue Badge scheme provides a national range of parking concessions for disabled people with severe mobility problems who have difficulty using public transport. The information via the link provided makes it clear who is entitled to a badge and how to apply for it.

British Red Cross – See under ‘Equipment’.

Disabled Motoring UK - www.disabledmotoring.org

- Disabled Motoring UK is a campaigning charity for disabled drivers, passengers and Blue Badge holders.
- We lobby government & businesses across the UK in order to improve parking, refuelling and access provision for disabled people, so that they can access the goods and services that they need. We also campaign for and support passengers, scooter and wheelchair users, families and carers.
- Our information officers can answer your questions about accessible parking, vehicle adaptations, congestion charging and other issues that affect our members.
- Our monthly magazine, Disabled Motoring, includes information on our current campaigns, the latest news and reviews of vehicles, scooters and mobility aids as well as features on everything from accessible holidays to vehicle reviews. The magazine is free to members, who also benefit from a wide range of concessions and our confidential casework service.

Freedom Pass – www.londoncouncils.gov.uk/services/freedompass/applying/disabledpass.htm

- The **Freedom Pass** is a concessionary travel scheme to provide free travel to people who have a disability. It is a national scheme and applications are handled by your borough of residence. The link provided here is for people living in London and it shows eligibility requirements.

Government information about driving with medical conditions and disability -

www.gov.uk/browse/driving/disability-health-condition

Government regulations regarding driving and medical conditions and disability - www.gov.uk/driving-medical-conditions

- You must tell DVLA if you have a driving licence and:
 - you develop a ‘notifiable’ medical condition or disability
 - a condition or disability has got worse since you got your licence
- Notifiable conditions include epilepsy, strokes, other neurological and mental health conditions, or physical disabilities and visual impairments that could affect your ability to drive safely.
- If you’re in Northern Ireland you must [contact the Driver and Vehicle Agency \(DVA\)](#).

Motability - www.motability.co.uk

- The Motability Scheme enables disabled people to exchange either their Higher Rate Mobility Component of Disability Living Allowance/Personal Independence Payment or their War Pensioners' Mobility Supplement to obtain a new car, powered wheelchair or scooter.

Mobility Road Show - www.mobilityroadshow.co.uk

- Gives anyone with a mobility problem - drivers, passengers, adults or children - the chance to see what is available to help solve that problem and most importantly to try out and evaluate the options.

Employment Support

The following organisations provide information, support and/or legal advice in relation to employment issues.

AbilityNet – See under ‘Computer Access’.

Access to Work - www.gov.uk/access-to-work/overview

- An Access to Work grant helps pay for practical support if you have a disability, health or mental health condition so you can start working, stay in work or start your own business. How much you get depends on your circumstances. The money doesn't have to be paid back and will not affect your other benefits. Access to Work is only available in England, Scotland and Wales.

Backup Trust – See under ‘Information & Support’.

Disability Rights – See under ‘Information & Support’.

Neurosupport – www.neurosupport.org.uk

- Neurosupport offers return to work and employment advice, legal advice, benefits advice and information and support to people affected by neurological conditions and their carers. They are based in Liverpool.

Spinal Injuries Association – See under ‘Information & Support’.

Work Choice - www.gov.uk/work-choice/overview

- Work Choice is an employment programme that supports people with disabilities and long-term health issues who face real barriers when it comes to finding and keeping work. It is offered through other organisations throughout the UK.

Equipment

The following organisations provide information on, access to and funding for equipment.

Aspire – www.aspire.org.uk

- Aspire offers practical support to people living with a spinal cord injury in the UK so that they can lead fulfilled and independent lives in their homes, with their families, in work places and in leisure time.
- They give funds to people to help them buy the specialist equipment they need to live a more independent life.
- Provide services to patients in the Spinal Cord Injury Centres ensuring they get the support and services they need and have independent access to a computer. They also provide accessible properties around the UK that can be used on a short-term basis whilst someone is adapting their own property or hunting for a permanent home.

British Red Cross - www.redcross.org.uk

- The British Red Cross provide a range of services to support people in the UK including equipment, care and transport.

Disability Living Foundation - www.dlf.org.uk

- Disabled Living Foundation provide independent information about equipment to aid daily living to professionals and disabled people.

Living Made Easy - www.livingmadeeasy.org.uk

- Provides clear, practical advice on daily living equipment.

Mobility Trust - www.mobilitytrust.org.uk

- The mobility trust provides support for people unable to access suitable wheelchairs from statutory services.

Remap - www.remap.org.uk

- Remap is a national charity working through local groups of skilled volunteers to help people with disabilities achieve independence and a better quality of life. We make or modify equipment when nothing suitable is available through mainstream sources. Items are tailor-made to be suitable for individual needs and to make a real difference to people's ability to rise to a particular challenge and achieve something not otherwise possible for them.

The ACT Foundation - www.theactfoundation.co.uk

- ACT provides grants to individuals and other charities, principally in the UK, with the aim of enhancing the quality of life for people in need.

The Disability Equipment Register - www.disabreg.pwp.blueyonder.co.uk

- The largest single source guide of used secondhand Disability Equipment in the UK. A not-for-profit organisation providing a service for disabled people and their families to enable them to buy and sell items of used disability equipment on a direct One-to-One basis.

Ex-services Support

The following organisations provide support to ex-service men and women and their families.

Legionline (Royal British Legion) - www.britishlegion.org.uk

- The Royal British Legion provides practical care, advice and support to Armed Forces personnel, ex-Service men and women of all ages and their families.

Royal Navy Benevolent Trust - www.rnbt.org.uk

- The Royal Navy Benevolent Trust provides support for former naval personal and their families.

SSAFA - www.ssafa.org.uk

- SSAFA provide practical support for members and former members of the Armed Forces, including the Volunteer Reserve Forces and Nursing Services, and their wives, former wives, husbands, former husbands, families, widows, widowers, children and other dependants.

Financial Issues

The following organisations provide information related to financial issues.

Age UK - <http://www.ageuk.org.uk/money-matters>

- Age UK provide a range of information and advice about a wide range of money matters from paying for services to claiming benefits.

Citizens Advice Bureau - www.citizensadvice.org.uk

- Citizens Advice provide a free and impartial money advice service that offers help to those struggling with financial difficulties. It also offers benefits advice. You can find details in the local telephone directory, in libraries or on their website.

National Debtline - www.nationaldebtline.co.uk

- National Debtline offer free confidential advice on how to deal with debt problems.

Stepchange - www.stepchange.org

- Stepchange (formerly: Credit Consumer Counselling Service) is a registered charity whose purpose is to assist people who are in financial difficulty by providing free, confidential debt advice and no-fee debt solutions. Their online debt counselling service, Stepchange Debt Remedy, provides instant, anonymous advice, a personalised budget and a realistic recommendation. No commitment is required and the service is free of charge.

Furniture

The following organisations provide information on accessing furniture.

Furniture Reuse Network - www.frn.org.uk

- The FRN is the national body which supports, assists and develops charitable re-use organisations across the UK. Includes searchable database of local reuse organisations for access to furniture and home goods.

Grants

The following organisations provide information about access to grants and other sources of funding.

Charity Search - www.charitysearch.org.uk

- Charity Search delivers a free service which helps older people in genuine financial need receive the support that may be available to them from a variety of charitable sources.

Elizabeth Finn Care - www.elizabethfinncare.org.uk

- Elizabeth Finn Care gives money to help people who have less than £4,000 in savings and, lacking enough household income. They help people whose former careers have been interrupted or ended through circumstances beyond their control: physical or mental illness, redundancy, family breakdown, or those struggling on low income in retirement.

Grants for individuals - www.grantsforindividuals.org.uk

- Website of the directory of social change. Has facilities to allow individuals to look for grant giving organisations based on their circumstances.

Turn2us – www.turn2us.org.uk

- Turn2us helps people in financial need gain access to welfare benefits, charitable grants and other financial help – online, by phone and face to face through our partner organisations. Turn2us is part of Elizabeth Finn Care.

Disability Grants - www.disability-grants.org

- Lists charities that provide grants for many categories of needs. The website also mentions when they can be available from the government, NHS or local council.

Holidays & Respite Breaks

The following organisations provide grants for holidays and respite breaks.

Accessible holiday information - <http://www.hadnet.org.uk/services/information-advice/accessibleholidays.aspx>

Disability grants for holidays - <http://www.disability-grants.org/holiday-grants.html>

- Lists organisations that provide grants for holidays.

Family Holiday Association - www.fhaonline.org.uk

- The Family Holiday Association considers grants to help families on low income to have a break.

Link to sites helpful for planning a holiday

- www.spinal.co.uk/page/holiday-links
- www.hadnet.org.uk/services/information-advice/accessibleholidays.aspx

Kiloran Trust - www.kilorantrust.org.uk

- The Kiloran Trust, a registered charity, was established to provide residential supportive breaks to those caring for a sick, elderly, dependent relative at home who feel the need of a break away.

Vitalise - www.vitalise.org.uk

- Vitalise is a national charity providing short breaks (respite care) and other services for people with disabilities, visually impaired people, and carers.

Respite Association - www.respiteassociation.org

- Will consider assistance in the funding of respite care for disabled, sick, elderly or terminally ill persons in order that their regular carer can be allowed to take a much needed break.

Housing

The following organisations provide information and grants for housing adaptations.

Care & Repair (England) - www.careandrepair-england.org.uk

- Care and Repair England is a charity set up to improve housing and living conditions of older and disabled people in England.

Care & Repair (Wales) - www.careandrepair.org.uk

- Care and Repair Wales is a charity set up to improve housing and living conditions of older and disabled people in Wales.

Disability grants for housing adaptations - <http://www.disability-grants.org/grants-for-housing.html>

- Lists organisations that provide grants for housing adaptations.

Elderly Accommodation Counsel (EAC) – See under ‘Ageing & Elderly’.

Fold Housing Trust (Northern Ireland) - www.foldgroup.co.uk

- A non-profit organisation who provides information and advice on home improvements and repairs in Northern Ireland.

Foundations - www.foundations.uk.com

- National Body for home improvement agencies.

Household & Energy Bills

Anglian Water Trust Fund - www.anglianwater.co.uk

- The Anglian Water Assistance Fund supports people in the Anglia and Hartlepool Water region and administers a grants programme aimed at reducing water and sewerage debt for customers experiencing poverty and hardship throughout the region.

Auriga Services - www.aurigaservices.co.uk

- Provide Information on all the utility companies charitable grants

The British Gas Energy Trust - www.britishgasenergytrust.org.uk/grants_to_individuals/index.html

- The British Gas Energy Trust provides grants to clear gas and electricity arrears. They clear other priority debts, including water and sewerage. They also consider grants to purchase essential household items or assistance with funeral payments.

EDF Energy Trust - www.edfenergytrust.org.uk

- EDF Energy Trust will consider grants to individuals and families to clear domestic energy arrears and other essential household bills or costs.

Energy-saving improvements (heating, etc.) -

www.scope.org.uk/heating?gclid=CLKGw77F7roCFfHtAodkD4A-w

- You could qualify for free energy-saving improvements from npower like a new efficient boiler, or wall or loft insulation that could help keep your heating costs down or make your home warmer. This is available as part of a government scheme so you don't even have to be an npower customer.
- If you, or a member of your household, are receiving Government benefits such as those listed, then you may* qualify. (*additional criteria may apply to some benefits)
 - Income support
 - Income-related employment and support allowance
 - Income-based job seekers allowance
 - Working tax credit and have an annual income of £15,860 or less
 - Child tax credits and have an annual income of less than £15,860
 - State pension credit
- There are 4 steps to find out if you qualify
 1. Complete [npower's energy-saving improvements pre-assessment form online](#)
or
Freephone **0800 072 1745**
Mobile **0330 100 0052**
Open 8am to 6pm Monday to Friday.
 2. If you call, the npower adviser will ask you a few questions to see if you qualify. It's really simple and only takes a few minutes. You'll receive impartial advice about what is right for you.
 3. If you qualify, npower will arrange for an assessment visit at your home.
 4. The assessor will find out which improvements your home could benefit from under the scheme.
 5. You decide if you want to take up the offer and you don't need to be an npower customer.

Home Heat Helpline - www.homeheathelpline.org.uk

- Home heat helpline provide information and advice to people who are struggling with the costs of heating their home. They provide give information about benefits and grants and give you advice on making your home more energy efficient.

NEST (Wales) - www.nestwales.org.uk

- NEST is the Welsh Government's fuel poverty scheme. They provide information and advice to people who are struggling with the costs of heating their home. They provide give information about benefits and grants and give you advice on making your home more energy efficient.

Information and Support

The following organisations provide a range of information and support on benefits, careers, health, symptoms experienced by people living with TM/ADEM/NMO, and more.

Backup Trust - www.backuptrust.org.uk

- Our services include mentoring, wheelchair skills training and activity courses as well as support in getting back to work after an injury. All our services help to build confidence and independence.

Brain & Spine Foundation – www.brainandspine.org.uk

- They help people affected by brain and spine conditions.
- They have a telephone and email helpline staffed by nurses who specialise in neurological conditions.
 - Telephone - 0808 808 1000
 - Email - helpline@brainandspine.org.uk
- They also produce an excellent booklet on Transverse Myelitis which you can use to share with family, friends, carers, and employers to help them understand the condition and its impact on you. - http://www.brainandspine.org.uk/sites/default/files/documents/transverse_myelitis.pdf
- They have an excellent Frequently Asked Question section relating to treatment and diagnosis - <http://www.brainandspine.org.uk/frequently-asked-questions>

Disability Information and Advice Line (DIAL) - www.scope.org.uk/dial

- DIAL UK is a national organisation for a network of approximately 120 local disability information and advice services run by and for disabled people.

Disability Now - www.disabilitynow.org.uk

- Website for, about and by disabled people.

Disability Rights – www.disabilityrightsuk.org

- We produce high quality information, products and services developed by and for disabled people. We partner with the private and public sector, with the aim of improving business practices
- Provide a range of information on benefits, advice and work support issues and benefits training course; provides career advice to disabled students studying in England and support students who are studying in Wales and Scotland with general information on the Equality Act, welfare benefits and access to Higher Education; has helplines for independent living and disabled student queries; partner with The Equality Advisory Support Service (EASS), to provide support for disabled people who feel they may have been discriminated against; provided advice and information to parents and carers of disabled children and young people about personal budgets; provide training to help disabled people with the skills and confidence to improve their lives and make a difference to the lives of many other disabled people across every sector of society

Government – Benefits, Money Advice, Statutory Services - www.gov.uk

- Information portal for all public services in the UK.

Health & Social Care in Northern Ireland - www.hscni.net

- Information for health and social care services in Northern Ireland

Neurosupport – See under ‘Employment Support’.

NHS Choices – www.nhs.uk

- Main portal of information on services from the NHS

NHS Direct - www.nhsdirect.nhs.uk

- Gives health information and advice. Available 24 hours a day and 365 days a year

NHS Direct Wales - www.nhsdirect.wales.nhs.uk

- Gives health information and advice to people in Wales. Available 24 hours a day and 365 days a year

Queen Elizabeth’s Foundation for Disabled People - <http://qef.org.uk/>

- We work with people with physical and learning disabilities or [acquired brain injuries](#) to gain new skills and increase independence. Whether it’s learning everyday life skills, rebuilding a life affected by brain injury, acquiring the skills to drive a specially adapted car or training for future employment, we support disabled people to achieve goals for life.

Spinal Injuries Association – www.spinal.co.uk

- Provides a range of support from a helpline, benefits advice, information about adapting to and living with a spinal cord injury (whether it has been acquired through injury or illness), return to work support, having prescriptions delivered, courses and more. The SIA offers free membership.

Legal

Disability Law Society - www.dls.org.uk

- Provide information and advice on all aspects of disability law.

Law Society - www.lawsociety.org.uk

- The law society can signpost to solicitors who offer legal aid.

Legal Advice Now - www.advicenow.org.uk

- Advicenow is an independent, not for profit website providing online information and advice on rights and legal issues

Neurosupport – See under ‘Employment Support’.

Managing Symptoms

The following contains books, information and organisations which provide information and support on the various symptoms people living with TM/ADEM/NMO experience. If there are organisations that provide information on a range of symptoms, they are listed in this section under 'Organisations'.

Also refer to the conference presentations referred to under 'Transverse Myelitis and related conditions of ADEM & NMO' for presentations which are about managing symptoms.

BOOKS & ARTICLES

After The Diagnosis: Transcending Chronic Illness by Dr. Julian Seifter, MD (2010)

- A book written by a doctor who has a chronic condition himself, about how to live with a chronic condition.

A Letter to Patients With Chronic Disease - <http://more-distractable.org/musings/2010/07/14/a-letter-to-patients-with-chronic-disease>

- This blog post was written by a GP, Dr. Rob, and explains from the GP perspective what it is like to treat a person living with a chronic condition and ideas on how to work with doctors.

Books written by people about their experiences of living with TM or ADEM

- In My Dreams, I'm Dancing by Ruth Wood
- Hannah Same Both Ways, by Hannah Rose
- Taking Charge: A Journey of Recovery, by Graham Martin
- The Best Seat in the House How I Woke Up One Tuesday and Was Paralyzed for Life by Allen Rucker
- To Get Back Home: A Mysterious Disease: A Fight for Life by Wendy Chapin Ford (about ADEM)
- Getting Better: My Journey through Transverse Myelitis and Lessons for Health Care Professionals, Patients and Families by Keith J. Launchbury

COPING EMOTIONALLY & DEPRESSION

Coping with a Chronic Illness -

<http://www.alpineguild.com/COPING%20WITH%20CHRONIC%20ILLNESS.htm>

- An article on coping emotionally with a chronic illness.

Demoralisation & Depression in Multiple Sclerosis and Transverse Myelitis -

<http://myelitis.org/newsletters/v8n1/newsletter8-1-02.htm#.UdyUpW1gE7w>

- An article by Dr. Adam Kaplin of the Johns Hopkins Project Restore Team on demoralisation and depression in MS and TM.

Depression Alliance - www.depressionalliance.org

- Depression Alliance is the leading charity in the UK for anyone affected by depression, and we can help you meet and chat to others in your local area, join a self-help group, and learn more about depression, treatment and recovery. We also campaign to end the stigma of depression and to raise awareness of what it means to live with it

In Control - www.in-control.org.uk

- In Control operates as an extensive community network that is working for change and to provide people with the knowledge, power and tools to control their support.

CONTINENCE

Bladder & Bowel Foundation – www.bladderandbowelfoundation.org

- The B&BF is the UK wide charity for people with bladder and bowel control problems. B&BF provides information and support services, including a confidential helpline, for anyone affected by these conditions as well as their families, carers and healthcare professionals.
- Their helpline is 0845-345-0165.

InContact - www.incontact.org

- Information about incontinence products and supplies

Continenence Foundation - www.continenence-foundation.org.uk

- Provides information on the treatment, prevention, causes, types and living with continence.

FATIGUE

Managing fatigue - <http://www.butyoudontlooksick.com/navigation/BYDLS-TheSpoonTheory.pdf>

- Hints and tips on managing fatigue by explaining The Spoon Theory.

ORGANISATIONS

Brain & Spine Foundation – See under ‘Information & Support’

- They have a helpline you can call.

Spinal Injuries Association – See under ‘Information & Support’

- They have a helpline you can call.

PAIN

British Pain Society – www.britishpainsociety.org

- The British Pain Society is the largest multidisciplinary professional organisation in the field of pain within the UK. Our membership comprises medical pain specialists, nurses, physiotherapists, scientists, psychologists, psychiatrists, general practitioners, occupational therapists and other healthcare professionals actively engaged in the diagnosis and treatment of pain and in pain research for the benefit of patients.
- www.britishpainsociety.org/patient_home.htm - Via this link, there is information that may be of use to people suffering with pain, including a list of UK-based patient organisations, a frequently asked questions section and a suggested reading section.

Pain Concern - www.painconcern.org.uk

- Pain Concern provides information on pain and support to people with pain and those who care for them. It also campaigns to raise awareness about pain and improve the provision of pain management services.

- It has a helpline – 0300-123-0789.

Pain Support - www.painsupport.co.uk

- Provides information and pain relief techniques for those with chronic pain. There is also a regular email Newsletter, a lively Discussion Forum and a Contact Club for making new friends, plus our Shop for books, relaxation CDs and downloads.

Pain Toolkit – www.pain toolkit.org

- Information on pain and self-care

Understanding Pain in Transverse Myelitis – <http://myelitis.org/resources/tma-blog/understanding-pain-in-transverse-myelitis/>

- Article by Dr. Benjamin Greenberg on understanding pain in Transverse Myelitis

Physiotherapy

Association of Chartered Physiotherapists Interested in Neurology (ACPIN) - www.acpin.net

- ACPIN is one of the largest Professional Networks recognised by the [Chartered Society of Physiotherapy](http://www.csp.org.uk). It is concerned with all aspects of physiotherapy related to the needs of neurologically impaired adults and their relatives and carers.

MS Therapy centres –www.msntc.org.uk

- There are over 50 MS therapy centres throughout the UK and each is an independent charity. Sometimes people living with TM, ADEM and/or NMO may be able to use their services. Check if there is a MS Therapy Centre where you live and ask if you can become a member.

Recreation

Cinema Exhibitors Association - www.ceacard.co.uk

- The C.E.A. Card allows the cardholder to obtain ONE free ticket for a person to provide assistance required as a result of the cardholder's disability during their visit to the cinema, provided that a full price ticket is purchased by the cardholder for the same film.

Disabled Ramblers – www.disabledramblers.co.uk

- The Disabled Ramblers exists to help mobility-challenged people get back out into the countryside.

Gardening for the Disabled Trust - www.gardeningfordisabledtrust.org.uk

- Grants to people to continue gardening despite disability or advancing illness.

Stichlinks – www.stichlinks.com

- A charity, which uses crafts, particularly knitting, to increase wellbeing. They also provide information on how you can set up your own Stichlinks knitting group.

Regional Support

The Fudge Trust - <http://fudgetrust.co.uk/about-us>

- Supports people in need in the Warminster area

Bristol's Charity Trust - www.bristolcharities.org.uk

- An umbrella organisation that administers funds from a number of small charities supporting people in the

The Chippenham Borough Lands Charity - www.cbhc.org.uk

- Supports people in need in the Chippenham area.

St. John's Charity - www.stjohnsbath.org.uk

- Supports people in need that live in the Bath area.

Colchester Catalyst Trust - www.colchestercatalyst.co.uk

- Provide funding and support for people living in North East Essex particularly where assistance is not available from statutory organisations

Sport

Riding for the Disabled Association (RDA) - www.rda.org.uk

- Providing riding, carriage driving, vaulting and showjumping opportunities to people with disabilities all over the UK.

Support through Sport UK - www.supportthroughsport.co.uk

- A charity that believes that sport has the power to improve lives.

Wheelpower - www.wheelpower.org.uk

- The national charity for wheelchair sport provides opportunities, facilities and equipment to enable disabled people to participate in sport and lead healthy active lives.

Travel Insurance

The Transverse Myelitis Society has produced a separate document regarding travel insurance. If you would like a copy, please send an email to info@myelitis.org.uk

Transverse Myelitis and related conditions of ADEM & NMO

This section contains conference presentations, information, and organisations that focus on TM, ADEM and NMO.

CONFERENCE PRESENTATIONS

Johns Hopkins TM Center 2013 Regional Transverse Myelitis Clinical Care Symposium –

www.youtube.com/playlist?list=PLXi60bEckjnWpjEkRgY4Q1X6Tp_6SHSeI

- Presentations from this symposium which took place on 15 June 2013 in Baltimore, Maryland at the Johns Hopkins TM Centre.

2013 Rare Neuroimmunologic Disorders Symposium - <http://myelitis.org/portfolio-view/2013-rare-neuroimmunologic-disorders-symposium/>

- Presentations from this symposium which took place in Dallas, Texas in October 2013.

Transverse Myelitis Association conference presentations - www.youtube.com/user/transversemyelitis

- The TM Association has loaded over 250 presentations from various conferences on to YouTube. Talks cover a wide range of subject matter from research to symptom management.

Transverse Myelitis Society conference in April 2011 –

<http://www.youtube.com/playlist?list=PL7C4082CC1A44D2D9&feature=plcp>

- Presentations from this conference are available on YouTube

Transverse Myelitis Society 1 day conferences in May 2014

- Presentations and notes from 3-May-2014 conference at The Walton Centre/Aintree Hospital in Liverpool – www.myelitis.org.uk/news-blog/may-2014-conferences
- Presentations and notes from 17-May-2014 conference at the John Radcliffe Hospital in Oxford – www.myelitis.org.uk/news-blog/may-2014-conferences

INFORMATION

A Primary Care Guide to Transverse Myelitis – http://myelitis.org/wp/wp-content/uploads/2013/03/Primary_MD_Guide_article.pdf

- A guide to treating Transverse Myelitis written for physicians/GPs

Brain & Spine Foundation – www.brainandspine.org.uk

- They also produce an excellent booklet on Transverse Myelitis which you can use to share with family, friends, carers, and employers to help them understand the condition and its impact on you. - http://www.brainandspine.org.uk/sites/default/files/documents/transverse_myelitis.pdf

Demoralisation & Depression in Multiple Sclerosis and Transverse Myelitis -

<http://myelitis.org/newsletters/v8n1/newsletter8-1-02.htm#.UdyUpW1gE7w>

- An article by Dr. Adam Kaplin of the Johns Hopkins Project Restore Team on demoralisation and depression in MS and TM.

Health Condition Insight Report into Transverse Myelitis -

http://www.myelitis.org.uk/uploads/1/5/8/2/15824690/health_condition_insight_report_into_tm_-_final_for_tms_members.pdf

- This report was completed by the Transverse Myelitis Society in October 2013 for use by assessors at ATOS and CAPITA when assessing people living with Transverse Myelitis for the Personal Independence Payment (PIP). PIP helps with some of the extra costs caused by long-term ill-health or a disability for UK citizens aged 16 to 64.)

Introductory leaflet on TM and the TM Society written by the TM Society –

- www.myelitis.org.uk/uploads/1/5/8/2/15824690/intro_tri-fold_apr_2013_v2.pdf
- www.myelitis.org.uk/uploads/1/5/8/2/15824690/tmsffleafletsept2013.pdf

Understanding Pain in Transverse Myelitis –<http://myelitis.org/resources/tma-blog/understanding-pain-in-transverse-myelitis/>

- Article by Dr. Benjamin Greenberg on understanding pain in Transverse Myelitis

ORGANISATIONS

Devics Association - www.devic.org.uk

- UK based site providing information about Devics Disease (Neuromyelitis Optica)

List of NHS neurological centres in the UK - www.brainandspine.org.uk/neurological-centres-in-the-uk

NHS NMO Specialised Service - www.nmouk.nhs.uk/nmo-service

- Provides information about the NHS Neuromyelitis Optica (NMO) Service including diagnosis, treatment, managing symptoms and living with NMO.

Transverse Myelitis Association – www.myelitis.org

- USA/worldwide member organisation for those with TM and related conditions of ADEM and NMO

Transverse Myelitis Society – www.myelitis.org.uk

- UK based member organisation for those with TM and related conditions of ADEM and NMO