



York & District ME Support Group Useful Contacts December 05

DISCLAIMER: The inclusion of information of any kind in this document does not imply a recommendation or guarantee of accuracy.

ACTION FOR ME 0845 123 2380

One of two large national Organisations. They offer a quarterly newsletter and other services. They have counselling, listening ear service, welfare benefits help and children's service and website, residential rehabilitation courses. They can also put you in touch with special interest groups. <http://www.afme.org.uk/>

For children: <http://www.a4me.org.uk/>

ME ASSOCIATION Offers 'Connect', information and support service (members) 0870 444 1835 (non-members) 0870 444 183610-12 noon, 2.00-4.00pm 7.00-9.00pm. Newsletter.

<http://www.meassociation.org.uk/>

25% ME GROUP 01292 318611

For people with severe Myalgic Encephalomyelitis. Services include: newsletter; talking book service; group library.

<http://www.btinternet.com/~severeme.group/>

AYME - ASSOCIATION OF YOUNG PEOPLE WITH ME

Help line 08451 23 23 89. Free for people with ME between 5 and 25 years old and parents/ carers. Telephone helpline, books and videos available and an opportunity to make friends with other people affected by ME. Produce a magazine and can help out with problems about schools and home tutors etc. www.ayme.org.uk

ME NORTH EAST 0191 389 2222

Provides information and advice for people living in the North East. Contact list for young people.

NATIONAL ME SUPPORT CENTRE 01708 378050

Provides inpatient and outpatient care of patients with chronic fatigue syndromes of all types. Offers counselling and is also linked to the Regional Neurological Unit at Oldchurch Hospital where facilities exist for inpatient assessment and rehabilitation. <http://www.nmec.org.uk>

The Young Me Sufferers Trust (TYMES TRUST) 01245 401080.

Supports young people and carers. Free up to age 26, subscription over 26. Partnership with virtual education provider, members over 16 can access free virtual education. Magazine, Advice Line, Tymes Trustcard (a "pass card" for school) supported by Secondary Heads Association.

NEIGHBOURING SUPPORT GROUPS

Leeds: Enquiry Line 0113 298 2070

Doncaster (Leger): Mike Valentine 01302 787353

Hull & East Yorkshire: Gillian 01964 550530

Middlesborough: 01642 324994

Northallerton: Shirley Sneddon 01609 770921

We hope the following gives an idea of the other help available. The list isn't exhaustive and is as up to date as possible – if you come across a local organisation to add to the list or find any errors do let us know. Further local information (and often advice eg on benefits) can be found from the websites on page 4, from your local council, CVS, or disability organisation such as:

YORK DISABILITY INFORMATION AND ADVICE CENTRE (DIAC)
01904 638467

SCARBOROUGH DAG (Disablement Action Group) 01723 379397

SELBY & DISTRICT DIAL 01757 210495

WHITBY & DISTRICT DAG (Disablement Action Group) 01947 821001

PRACTICAL SUPPORT & INFORMATION

CONTACT A FAMILY 0808 808 3555

Gives information and advice to families of disabled children and encourages mutual support through a network of local and national support groups Mon-Fri 9am-5.00pm.

FAMILY FUND TRUST 0845 130 45 42

York based organisation that helps families of disabled and seriously ill children under the age of 16. Give grants eg holiday and leisure, and, information related to the care of the child such as benefits, holidays and transport.

CENTRE FOR SEPARATED FAMILIES 01904 610268 (York)

07876498992(Harrogate) 07876 498998 (East Coast) advice on many issues such as benefits, housing and money to their members.

PACT YORKSHIRE: 01904 639056

A wide-ranging programme of direct services and development initiatives designed to support and empower children with disabilities and their families. Mon-Fri 9am-5pm

SPECIAL FAMILIES - YORK 01904 629640

SPECIAL FAMILIES - RYEDALE 01653 699000

Parent and family support group for families who have a disabled child

YOUNG CARERS SERVICE

YORK 01904 724466/SCARBOROUGH01723 378582

Offers advice information and support for young carers (under 18).

YOUTH ENQUIRY SERVICE (YES) 01904 623850

YES offers free and confidential information and support to young people up to 25. Counselling in York by appointment.

RYEDALE YOUTH SERVICE 01653 694122

Free and confidential information and support to young people (11-25) in and around Malton.

AGE CONCERN

Selby 01757 704115/Scarborough and District 01723 3790580/

York 01904 627995 or 621020

Gives a wide variety of help, practical support and advice to older people and their relatives.

OLDER CITIZENS ADVOCACY YORK 01904 676200

Advocacy and information to people over 60. Promotes the rights of individuals experiencing disagreements or complaints about services care treatment and other social or health related issues.

CARERS UK

Carers UK help line 0808 808 7777 Information and support through a nationwide network of groups.

CARERS' CENTRE - YORK AND SELBY DISTRICT

Selby 01904 724314/York 01904 724466

Advice information and support for carers. Produces free newsletter and organises courses. Works with carers carer groups and organisations to improve services for carers. Offers a service to young carers (under 18).

COPMANTHORPE COMMUNICARE 07843012629

For locals in need of help with shopping transport to hospital clinics library and so on. In an emergency can provide an emergency baby or 'granny' sitter. (Caroline Kett)

CROSSROADS

Selby 01757 210013/York 01904 790200 and 01904 785158
Gives practical reliable support to the carers of children and adults with care needs and to young carers. Trained support workers provide support at home.

HUNTINGTON GOOD NEIGHBOURS' ASSOCIATION 01904 637009

A volunteer scheme for Huntington and Earswick residents in case of emergency or for short-term basis. Services offered include visiting shopping, transport and household jobs.

PERSONAL ASSISTANCE SCHEME AND DIRECT PAYMENTS

Harrogate/Craven 01765 605515 /Richmondshire/Hambleton 01423 323652/Scarborough 01723 500043/York 01904 427251
Advice on direct payments to disabled people to pay for community care Personal Assistance Scheme gives support to disabled people aged over 18 requiring seven-plus hours per week personal assistance for independent living in the community. Help/advice given in the employment of personal assistants.

RYEDALE CARERS SUPPORT SCHEME 01751 472232

Supports those who are caring for an elderly or disabled person at home. Runs groups in Pickering, Malton and Kirkbymoorside.

SCARBOROUGH AND RYEDALE CARERS RESOURCE 01751 473727

BRITISH RED CROSS

Malton 01653 696188 /York 01904 691021
Often provide medical loan schemes e.g. wheelchairs and commodes. In York also Transport (wheelchair accessible minibus) and home visiting hand/shoulder massage.

YOUR LOCAL COUNCIL e.g. York 01904 613161

Contact point for council services including Occupational Therapy (who can provide aids such as chair raisers to help you manage and housing adaptations such as ramps) and other social service provision.

EQUIPMENT HIRE – OTHER. Some local disability organisations eg Whitby DAG provide equipment for hire. Selby DIAL has some sma;; items which can be purchased, and a short-term wheelchair hire service, as does Shopmobility York. (See addresses on page 1 and 3). Local disability organisations often provide RADAR keys for disabled toilets. (£3.50) (Also from RADAR website).

WILLIAM MERRITT DISABLED LIVING CENTRE 0113 305 5332

Information and advice on aids for disabled living from Leeds.

CALIBRE 01296 432 339

Free lending library of books on audiocassette, by post, to people with difficulty reading.

ADVOCACY ALLIANCE 01723 363910

For people who need in help in getting their voice heard Scarborough,

This document is available in large print

Filey, Whitby and Ryedale areas. Letter writing, attending meetings, and put together complaints on health issues etc. Can home visit

CITIZENS ADVICE BUREAU

For free general advice including welfare benefits. See phonebook. (Also contact your local disability advice centre)

DISABILITY LAW SERVICE. 020 77919800

Free legal advice and representation service for disabled and families

RADAR 020 7250 3222

Advice for disabled people on employment, education, home-care community living assessments and other local authority services.

EDUCATION AGENCIES, TRAINING & VOLUNTARY WORK

ADVISORY CENTRE FOR EDUCATION 0808 800 5793

SKILL - National Bureau for Students with Disabilities .0800 3285050

CONNEXIONS INFORMATION SHOP 01723 373009

Based at Scarborough careers centre. Provides free information and advice on learning and training opportunities for local people.

FUTURE PROSPECTS 0800 834239

Free advice learning and work advice centre in York.

LETS (LOCAL EXCHANGE TRADING SCHEME)

Members trade goods and services with each other using a local currency. Offers and needs are listed in a directory. For details of your local branch see LETS website, or contact your local CVS.

RYEDALE VOLUNTARY ACTION 01653 600120

SCARBOROUGH DAG VOLUNTEER BUREAU – details on page 1.
SELBY DIS. ASSOC. OF VOLUNTARY SERVICE 01757 291111
VOLUNTEER CENTRE - COUNCIL FOR VOLUNTARY SERVICE
Scarborough CVS 01723 362205/York CVS 01904 621133
Information/advice on suitable local voluntary opportunities.

TRANSPORT & HOLIDAYS

YORK ACCESS GUIDE 01904 792023

A guide to access for the disabled in York available from DIAC and some other local disability organisations. For other areas contact local disability organisation.

CONCESSIONARY FARES AND HELP WITH TRANSPORT

In York the following help is available for disabled people:
(NB None-York residents should contact their local council, who will usually provide similar help): 1.Those with severe walking difficulties, which are not regarded as temporary, can apply for a blue (was orange) badge from the council. Very severely impaired York badge holders can obtain a parking permit for certain areas of city.

2.Reduced price travel with bus pass for York and North Yorkshire

3.National transport tokens bought at 75% discount for buses and taxis. Some taxi firms have wheelchair accessible vehicles in their fleet.

Also:

- 1.Train Concessions, £20 disabled railcard. Very restricted access eg benefit for very severe mobility problems/registered visually impaired
2. Train companies provide disabled assistance eg wheelchair, help with carrying bags – for information ring their special needs line.

DIAL A RIDE, SCARBOROUGH 01723 354434

Transport in adapted minibuses for elderly and those of any age who have difficulty using public transport due to mobility problems. Escorted shopping trips when needed.

DIAL A RIDE, YORK 01904 624455.

Door to door bus service to city centre Sainsburys, Tesco's, Asda and swimming pools for York Residents. Goes to different areas each day. Wheelchair accessible.

HAXBY HELPERS 01904 750266

A good neighbour transport scheme for the Haxby and Wigginton area of York.

RYECAT COMMUNITY TRANSPORT 01653 698888

Provides a transport service for elderly, disabled or sick people and for those with other specific needs.

SCARBOROUGH COMMUNITY TRANSPORT 01723 369034

Scarborough based, but provides services to surrounding rural areas for people who have difficulty in accessing public transport or taxis eg because of disability and, have no relatives who can help them.

SELBY DISTRICT VOLUNTEER AND COMMUNITY TRANSPORT CENTRE 01757 708036

WHEELS – YORK 01904 630080 or 726791 or 726786

Provide transport by car or minibus (adapted to take wheelchairs) for elderly or disabled people. Small charge.

SHOPMOBILITY National scheme providing electric scooters and/or electric or manual wheelchairs for use in city or town centres. Some schemes e.g. York offer longer-term hire of wheelchairs for a charge. Please ring before visiting as may need ID to register or to book in advance. There may be a small charge. For schemes throughout the UK see Shopmobility website, or ring a local disability organisations. Local schemes:

Leeds, 61 Vicar Lane 0113 246 0125

Leeds, White Rose Centre, 0113 277 3636

Manchester, The Trafford Centre 0161 747 8046

Sheffield, Meadowhall. 0845 600 6800

Wakefield, The Ridings 01924 787788

York. Piccadilly car park 01904 679222

Scooters in York also at B&Q warehouse, Asda, Tesco's, Sainsburys (mc), McArthur Glen Designer Outlet.

Also at Fountains Abbey, Bolton Abbey, Temple Newsam.

TRIPSCOPE 0845 758 5641

Free advice on mobility problems and travel information (local, long-distance and international) for people who cannot walk very far, manage stairs, or get out and about in a wheelchair. Includes equipment hire abroad.

TOURISM FOR ALL 0845 1249971

Holiday information and advice for disabled people eg. about accessible accommodation and financial assistance. They also publish directories of nursing and residential homes which offer short term respite care.

DIAL and RADAR also give help and advice on holidays.

HEALTH PROVISION/ADVICE

EXPERT PATIENT – (For contact info see PALS – see over)
Volunteer led courses for people with chronic health problems.

NHS DIRECT 0845 4647

24-hour confidential help line for information and advice about health problems. Also have information about health information services late-night pharmacies and out-of-hours dentists etc.

www.nhs.uk gives users access to NHS services and other related sites. It includes information on local hospitals and services, waiting times, walk in clinics, dentists etc.

PALS – See the NHS section in your phonebook

For information and advice, and problems and complaints about local NHS services.

NHS PROVISION FOR PEOPLE WITH ME

Advice on finding a good GP is available from the national ME organisations or Dr Charles Shepherd's book. (See below).

A local GP can refer as follows:

Chronic Fatigue Clinic Seacroft Hospital (Leeds) (adults)

Physiotherapy Bootham Park Hospital (York) (adults)

Dr Nigel Speight University of Durham Hospital (children)

Your local paediatric services (children)

For treatment of related health problems eg a dietician or a pain clinic.

Sometimes (rarely) funding can be made available for referral to a national clinic such as the National ME Centre. For further details of these national clinics please contact ME Organisations.

TREATMENT IN THE PRIVATE SECTOR

The Group holds details of practitioners that some of our members have seen. Treatment approaches vary, and what helps some people may not suit you. It can also be expensive. Please contact the York and District ME line for further information.

EMOTIONAL SUPPORT

The National ME support organisations usually have a listening ear or counselling service for their members. Other provision includes:

1-2-1 COUNSELLING 01904 634748

A free and confidential general counselling service for people in York.

BRITISH ASSOCIATION FOR COUNSELLING 01788 550899

List of Counsellors in your area.

DEPRESSION ALLIANCE 08451232320

Information and advice on depression.

HAXBY & WIGGINTON COMMUNITY HELPLINE 01904 769176

A free listening and support service staffed by trained volunteers for residents of Haxby, Wigginton and surrounding area Tues 7pm-10pm or 24 hour answer phone.

MIND - YORK AND DISTRICT

Info line 01904 647349/Office 01904 647014

Aims to help those in mental distress and their carers/family. Information and advice by phone, letter and in person. Counselling and advocacy services (by appointment). Volunteer and user involvement.

PANIC ANXIETY DEPRESSION SUPPORT 01723 377524

Scarborough network of sufferers that can contact each other and talk, or give each other advice, either by phone, letter, email or personal contact. Put people in contact with any professional or other types of help needed, be it another group or professional counsellor.

RYEDALE COUNSELLING SERVICE 01653 690124

Free and confidential counselling for adult and young persons 13-19yr olds for people in Ryedale

SAMARITANS

National helpline 08457 909090/Scarborough 01723 368888/York 01904 655888 or 24-hr telephone 01904 671109.

TUKE CENTRE YORK 01904 430370

Provides a high quality psychotherapy and counselling service at an affordable price. Information about how counselling/psychotherapy may help you and details of the work of the centre.

WOMEN'S COUNSELLING SERVICE (YORK) 01904 652706

Counselling for local women on a wide range of issues.

COMPLEMENTARY THERAPIES

A list for complementary therapies is below. Private care can be an expensive option and a therapy, which helps some people, may not help you. For further information about private doctors and complementary therapists please contact national ME Organisations. Lists of qualified practitioners can be obtained from the Associations below. The Group holds details of some complementary therapists seen by local people or who have expressed an interest in ME/CFS.

THE BRITISH ACUPUNCTURE COUNCIL 020 8735 0400

THE SOCIETY OF HOMEOPATHS 0845 4506611

BRITISH HOMOEOPATHIC ASSOCIATION 0870 4443950

(A register of doctors who are also homeopaths)

GENERAL OSTEOPATHIC COUNCIL 020 7357 6655

THE BRITISH REFLEXOLOGY ASSOCIATION 01886 821207

OTHER

ACTION AGAINST ALLERGY PO Box 278, Twickenham TW1 4QQ
Support group for people with allergy and multiple chemical sensitivity

IBS NETWORK 0114 272 3253

NATIONAL CANDIDA SOCIETY 01689 813 039

Information on digestive disorders that can accompany ME.

ORGANOPHOSPHATE NETWORK 01579 384492

Exposure to organophosphate may act as a trigger for ME or produce a condition with similar symptoms.

BRITISH PAIN SOCIETY (020) 7631 8870

Offer a free booklet on managing pain. Informative website.

SAD ASSOCIATION PO Box 989, Steyning, BN44 3HG.

Have an £5 information pack and other information to help with this condition that causes winter depression due to lack of daylight.

WEB SITES

There is a vast amount of information on health, disability and ME related issues including sites for many of the organisations above eg NHS Direct.

FURTHER INFORMATION and/or advice is available from your local library, citizen's advice bureau or local disability organisation. The York Citizen's Guide 2005, which lists organisations in and around York, will be available soon.

On-line guides: York CVS: <http://www.yorkcvs.org.uk/citizensguide.htm> Scarborough & District <http://www.sdscvs.uk.com>

There are many good books on Chronic Fatigue Syndrome and ME available from good bookshops (and sometimes your local library) or online from the national ME organisations etc. These include Living with M.E. by Dr Charles Shepherd Vermilion ISBN: 0091816793 and Somebody Help Me Jill Moss Sunbow Books (specifically aimed at children)

The Group would like to thank the Leeds group for allowing us to use their list as a basis for this document.
Jenny Gilmore York & District ME Support Group 10/01/06

There are groups for friendship and sites where you can get advice, for example by e-mail, or, from message boards. You can also keep in touch with the latest research and other news eg by joining a list such as Co-cure. Do remember though, that the quality of information on the web varies.

Fairly comprehensive links pages to other useful sites from:

ACTION FOR ME - Links to separate site for children

<http://www.afme.org.uk/>

DIAL UK - general disability site <http://www.dialuk.org.uk/>

RADAR - general disability site <http://www.radar.org.uk/>

ME CHAT an e-mail support list for people with ME links to local support groups, (eg to Sussex Group with links to the websites of some private Doctors), discussion groups etc. <http://www.mechat.co.uk>

Information on ME and Other Health Problems include:

AXFORD'S ABODE - Research info on CFS/ME & links to medical sites

<http://freespace.virgin.net/david.axford/melist.htm>

CO-CURE - information forum, including info on research and theories

www.co-cure.org

IMMUNE SUPPORT.COM - Comprehensive American website on ME

and Fibromyalgia <http://www.immunesupport.com>

MERGE - aim to identify, and fund research www.mererearch.org.uk

US CFIDS ASSOCIATION - www.cfids.org

ABOUT.COM - Health and Fitness category - information on a variety of illnesses <http://about.com/>

SURGERY DOOR - Information on medical conditions etc and healthy living. Links to sites on healthy eating etc www.surgerydoor.co.uk

THYROIDUK Info on thyroid, links research etc <http://www.thyroiduk.org>

LYME DISEASE Info on Lyme www.ilads.org

For **Benefits** try links from AfME, DIAL etc and also government sites:

APPEALS SERVICE - Useful information if you are appealing against a benefits decision <http://www.appeals-service.gov.uk/>

DEPT FOR WORK AND PENSIONS - Includes information on benefits (and even the publications used by decision makers and doctors when deciding your case) <http://www.dwp.gov.uk/>

For **practical help** - See websites of organisations above and try:

ME TIPS - Lots of subjects. Severe ME section carries old Action for ME articles on managing severe ME can be accessed via

<http://www.trevwilliams.co.uk/metips>

DISABLED LIVING FOUNDATION - Extensive list of fact sheets on

choosing equipment www.dlf.org.uk

YOU'REABLE.COM - Comprehensive disability site: travel, equipment work, news etc. www.youareable.com

For **friendship or contacts** or try national organisations eg AYME (for children), ME chat (above) and it's link pages, or:

www.mecfparents.org.uk (for parents with ME);

aquamarinetuk@yahoo.co.uk (socialising network for UK ME sufferers

20-39 years); www.brainfog.org or www.meconnection.co.uk