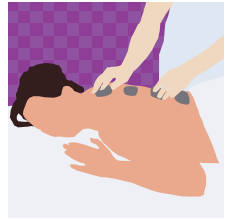
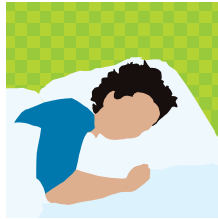
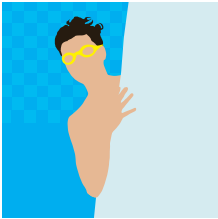


Tips for living with **MS**



written by and for people with multiple sclerosis

Introducing this book and the MS Trust...

The MS Trust is a charity working with and for the 85,000 people in the UK with multiple sclerosis (MS). Our vision is to enable people with MS to live their lives to the full.

This book came about when the MS Trust commissioned a research project into the information needs of people with multiple sclerosis. 2133 people took part through focus groups and questionnaires and many of these offered to others their 'tips' for publication in this book.

A key objective of the MS Trust is to offer information about MS which is positive and constructive. We do this through newsletters, through a range of publications and through our website. Even more importantly, our Information Service answers individual questions from people affected by MS from our unique library of books, journals and papers - questions as varied as are the people who ask them!

And what better information can there be than these tips gleaned from the experts who live with MS themselves?

Do you have a tip for someone living with MS?

We are collecting further ideas for a future second book of tips and to add to the Tips pages of our website. If you have a tip that's not covered in this book, send it to us at the address on the back cover.

Selection and sorting was challenging; we have broadly grouped the wealth of tips into sections:

- Maintaining a positive outlook Page 4-6
- Saving time and energy Page 7-10
- Getting around Page 11-12
- Making the most of benefits Page 13-14
- Medical matters Page 15-17
- Complementary therapies Page 18-19
- Nutritional needs Page 20-21
- Getting equipped Page 22-23
- Educational needs Page 24-25
- Work, rest and play Page 26-27
- Getting informed Page 28-29
- Useful contacts Page 30-39

Maintaining a positive outlook

There is no denying that living with MS can be difficult, frustrating and at times, frightening, particularly when you are first diagnosed. In the initial stages, it is natural to grieve for what you have lost. Over time, people find ways to adapt and come to terms with the changes that MS can bring, developing effective coping strategies which allow them to maintain a positive outlook and to live full lives. Here are some tips from people who have learnt to live with MS:

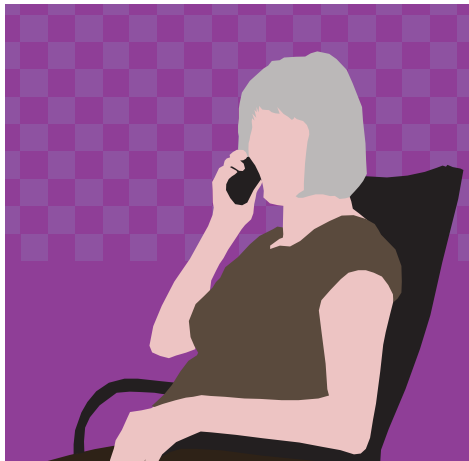
- The period after diagnosis is bound to be difficult. Try not to panic. Take your time to come to terms with your condition. Avoid making important decisions until you have adjusted to your new circumstances
- Don't give in to MS. Accept that your life is going to be different but it is most definitely not over!
- Don't dwell on the past and try not to worry about what may or may not happen in the future. Live your life for who you are now and devote all your energy and determination to exploring the full potential of what you have
- When you feel ready, arm yourself with as much knowledge as possible. This may help to allay some of your fears. For example, many people believe that everyone who has MS will end up in a wheelchair, which is far from the truth
- A good sense of humour can help to get you through difficult times. As one person with MS said, "A sense of humour should be given out when we are diagnosed and then put on a repeat prescription at very regular intervals"

- Keep a video of a favourite comedy programme or film on hand for times when you feel down. Laughter is a great tonic
- Be honest and open about how you feel. There is no need to put on a brave face all the time. If you go through a bad patch and life feels like an enormous struggle, talk to someone, be it family, friend, doctor or nurse. It really does help to share your feelings
- Ask for help and support when you need it, whether at home or in public – most people have no idea what it is like to have MS and need to be told how they can help
- Take each day as it comes. Try not to despair if you are having a really bad day – the chances are that tomorrow will be easier
- If you are prone to mood swings, warn your family and friends so they know what to expect!
- If you are feeling down, give yourself treats to keep your spirits up. Many people find that it helps their self-esteem to make a special effort with their appearance, even if they are feeling poorly



Maintaining a positive outlook

- Set yourself a challenge to achieve each day, however small
- Try not to let MS rule your life, although this is easier said than done! Keep in touch with people who do not have MS and don't allow yourself to be defined as an MS 'sufferer'. You are a person who happens to have MS – it does not change the essence of who you are
- Don't allow yourself to feel isolated. It can be really helpful to talk to other people with MS, either face to face, on the phone or over the Internet. Remember, you are not alone
- Never feel ashamed of having MS – it is a condition that you happen to have and not something you've brought on yourself
- Be realistic and know your limitations, but don't aim too low! MS is not an excuse for ducking out of life! Concentrate on what you can do, not what you can't



Saving time and energy

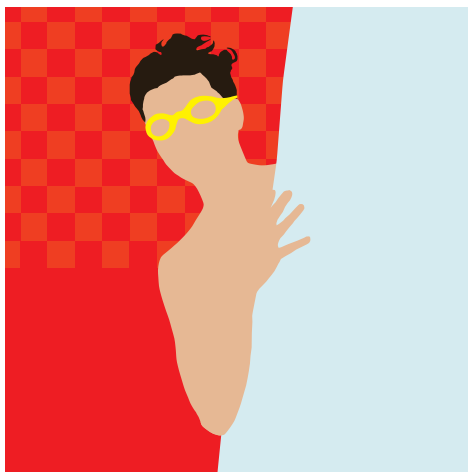
The saying 'every little helps' is certainly true in the case of MS. Small changes to the way you do things can add up to make a huge difference to how you get through the day. These are useful tips from people who live with MS:

In the home

- Fit a jar/bottle opener beneath a wall mounted kitchen cupboard. This requires very little strength to use
- Wear rubber gloves if you have trouble opening jars and bottles. Wind thick rubber bands round pens, pencils and door handles to make them easier to grip
- Sit on a bar stool while you do chores in the kitchen and attach a plastic bag for food rubbish to avoid numerous trips to the bin
- Buy small cartons of fruit juice with straws attached. They are easy to carry from the fridge if you use crutches and, even better, create no washing-up!
- Conserve your energy whenever possible. If you have to go upstairs to use the bathroom, save up other chores that need doing upstairs to avoid having to make separate journeys. Also, keep duplicate cleaning materials upstairs and downstairs
- Buy a laundry bag so that you can drag washing to the machine rather than having to carry it
- Make use of Meals on Wheels – it's not just for older people!

Saving time and energy

- If you have access to a computer, shop online for food and clothes. There is now a great choice available and you can try clothes on at your leisure
- The Internet can be a lifeline for anyone who is feeling isolated or who needs access to information or services. AbilityNet can help if you need to adapt your computer to make it easier to use



- An electric toothbrush is often easier to use than a manual one
- Cool water is generally better for symptoms than hot. When you take a bath or shower, start with tepid water and reduce the heat gradually
- If you have loss of feeling in your hands, invest in a water thermometer to avoid scalding yourself
- If closing your eyes makes you dizzy, wear swimming goggles to protect your eyes when washing your hair in the shower
- Opt for practical rather than fashionable clothing and footwear. Velcro fastenings are much easier to manage than fiddly buttons, zips and laces. If you use a wheelchair, a sarong – or a kilt! – can be a sensible alternative to a skirt or trousers, keeping you cool and making it easier to go to the loo

- When family and friends telephone, ask them to leave the phone ringing for longer to allow you time to answer. Also, invest in an answer-machine or use the free 1571 service provided by BT and some other providers
- If you struggle to pick something such as a piece of paper up from the floor, wet your fingers and you will find it easier to manage



Out and about

- If you tend to be forgetful, pin a list to your coat or bag to remind you what you need when you go out
- Use rucksacks or back packs rather than hand-held bags – they leave both hands free and don't throw you off balance
- Key contact details of friends and neighbours onto your mobile phone so that you can call for help if the need arises
- Don't be embarrassed to go to the front of the queue for the disabled toilet when, as usual, everyone else is using it!

Saving time and energy

Pacing yourself

- Prioritise tasks into those that are essential and those that can wait. Divide one major task into two more manageable jobs
- Get to know your limitations and work out a regime that suits you
- Save your energy for what you can do rather than struggling with tasks you find difficult – delegate these to other people!
- Listen to your body. Rest when you need to and learn to adapt to life at a slower pace. It can be helpful to divide the day into three parts: be active in two of them and rest well in the third
- Don't be tempted to overdo it if you are having a good spell – you might pay the price in a day or two!
- If you have a big event coming up, prepare for it by getting as much rest as possible beforehand



Getting around

When you have a condition like MS, your independence becomes even more precious. Make the most of the support that is available and plan ahead to avoid the unexpected:

- Learn to drive if you don't already do so. Some people only take lessons after they become disabled to avoid having to depend on others
- If you are nervous driving because your legs are weak, choose a car with hand controls
- Take advantage of the Motability scheme. Having access to a car, powered wheelchair or scooter can give you far greater freedom. Some people use their DLA payments to help fund a car or chair
- Keep a water sprayer in the car to cool you down
- A plastic carrier bag on the car seat can make it easier to swivel round
- In frosty weather, squirt de-icer across the roof of your car. It will run down the window on the opposite side of your car, saving you time and effort

Getting around

- Find out if there is a Shopmobility scheme in your area. This allows you to borrow wheelchairs and scooters at shopping centres, leaving you free to shop to your heart's content!
- Plan ahead before you go out: find out about accessible WCs, ramps and lifts etc to avoid unpleasant surprises
- All mainline stations should have ramps available to help you to get on and off trains. Let staff know in advance if you will require assistance
- Find out about the RADAR national key scheme, which provides access to public toilets which are usually kept locked
- Ask your local Council about concessionary fares on public transport or the Taxicard scheme
- If you are going somewhere special such as a restaurant or concert, phone ahead to see whether they can offer priority parking or special, seating arrangements
- Before you fly, contact the airline as they may be able to offer assistance in getting around, both before and after the flight. They may also be able to allocate a seat with extra leg room



Making the most of benefits

It can sometimes appear that the benefits system exists to make life difficult, rather than helping you to access the resources to which you are entitled! Don't despair. With persistence and patience, you will find your way through the maze:



- Find out what you're entitled to and claim it. Don't feel embarrassed about claiming and never feel that you are being a 'scrounger'
- Ask for help when filling in forms – there is a definite knack to them that only comes with experience! Make use of your local Citizens Advice Bureau (CAB). Their staff can be incredibly helpful with completing the mass of paperwork, much of which is badly designed and confusing. The MS Society and other organisations can also provide useful information and guidance
- When you fill in a benefit form, describe your worst days even if you are having a good spell
- MS is often 'invisible', ie not obvious to others, so don't give up if somebody in authority doesn't believe that you need help. Keep fighting for your rights

Making the most of benefits

- Don't be afraid of benefit tribunals. They exist to prevent fraud, not to prevent you from obtaining benefits
- If you have someone you depend on for help, make sure they also have access to the support they need
- Remember that Councils offer grants to assist people with disabilities to make adaptations to their home
- If you are unable to go out unaided, you may be entitled to free prescriptions
- The Direct Payments Scheme gives you control of the money allocated for your care. This can lead to a flexible relationship with a team of personal assistants and allow you to retain your independence. Phone your local council and ask to be put through to the Social Services help line
- Remember that you have paid your share in taxes and National Insurance contributions and now you are simply getting some of your money back!



Medical matters

MS is a complex and unpredictable condition. Symptoms can come and go and treatments may need to be adjusted from time to time. Be prepared to adapt to changing circumstances; these tips may help you make the most of your medical appointments:

Liaising with healthcare professionals

- Try to develop a positive relationship with your GP, who can be fundamental to ensuring that you receive the best possible care
- Ask if there is an MS specialist nurse in your area and, if so, ask to be referred
- Be honest with your doctors and specialists about your symptoms. If you are having a good day when you see the doctor, describe your symptoms on a bad day. Don't forget to tell them how you feel
- Write down any questions you have before your appointment and take a pad of paper so that you can make notes. It can also help to take somebody along with you
- If you disagree with your GP or neurologist, speak up! Your viewpoint is valid and you are the expert in your MS
- Don't immediately reject any treatment suggested by your doctor. Talk through your concerns and take time to consider each option carefully
- When you have an appointment with your doctor or nurse, try not to feel pressurised or rushed. Take your time and make sure that you get the most out of your appointment

Medical matters

Managing symptoms

- Try not to panic if symptoms change or new problems arise. Don't assume that every new symptom is caused by MS
- Keep a record of when symptoms appear and how long they last
- Ease swollen feet and legs by raising them above waist level, using pillows or a recliner. Work your calf muscles by pulling your foot upwards to reduce fluid
- Manage spasticity by 'breaking up' and changing rigid body posture, for example by bending the legs. When in bed, another good tip is to place a pillow lengthways just under the hip. This will roll the angle of the hips a few degrees, thus varying the pressure points. Bolster cushions can also be useful
- Do a few simple stretching exercises in bed before you get up in the mornings. Done regularly, this will make a real difference
- Regular physiotherapy can often be helpful. Ask your doctor
- If you have double vision, wear glasses (plain glass is fine) and cover one lens with tape or ask about plastic prisms for your glasses

- Be aware that fatigue is a symptom of MS and not just a sign of being unfit
- If you experience bladder or bowel problems, ask to be referred to a continence advisor – these problems can be successfully managed and a continence advisor can provide a great deal of valuable advice and support



- A cradle or cage to keep bed covers off your feet can help to relieve sore heels
- If you have regular injections but hate needles, ask your GP about hypnotherapy or auto-injectors
- The solution to your problem may be unexpected. Singing lessons can help relieve the symptoms of choking!

Complementary and alternative therapies

Some people with MS find that complementary therapies can help to ease symptoms or improve well-being. Everyone is different. What works for one person may do absolutely nothing for somebody else so be prepared to keep an open mind:

- Where possible, consult a practitioner who has been personally recommended to you (by a friend, health food store or doctor)
- Always tell your practitioner that you have MS
- Complementary therapies can be expensive. Know when to stop if you are not obtaining any benefit
- Don't believe that doctors are the only people who can help you. Some alternative therapies do work for some people
- Not everything works for everybody. Be prepared to try a range of treatments, but one at a time, so that you can tell which therapy works for you



Specific therapies that have been suggested as being helpful for some people include:

- Acupuncture
- Aromatherapy
- Cannabis
- Chinese medicine
- Homoeopathy
- Hyperbaric oxygen
- Hypnotherapy
- Massage
- Meditation
- Reflexology
- Reiki
- Tai chi
- Toning tables
- Visualisation
- Yoga



Nutritional needs

The link between MS and diet has not been proven but it is generally accepted that people with MS are well advised to follow a balanced, healthy diet. Some people find that dietary modification, in terms of taking specific supplements or avoiding particular foods, can be helpful:

- Follow general advice for a balanced diet. Include items from all five food groups: carbohydrates (bread, cereals and potatoes); fruit and vegetables; dairy products; meat, fish and alternatives; fat and sugar
- Reduce intake of saturated fats
- Maintain an intake of linoleic acid (present in sunflower and soya oils, beans, peas and lentils) and alpha linolenic acid (found in dark green leafy vegetables, broccoli, green pepper and oily fish)
- Consider taking supplements such as evening primrose oil or starflower oil. If necessary, consult a qualified dietician for advice on dosage
- Drink plenty of water



- To optimise nutritional value, eat fresh food wherever possible and cook vegetables lightly or eat them raw
 - Avoid excessive tea or coffee, particularly if you experience bladder problems, and replace with cranberry juice
 - Some people find ginger and mint to be helpful at relieving nausea
- 
- An illustration of a woman with long brown hair, wearing a dark blue top, sitting at a table. She is holding a white plate with orange-brown food and a green vegetable. She is also holding a white fork with a small piece of green vegetable on it. The background is a green and yellow checkered pattern.
- Limit intake of sugary food but if temptation is too much, try the rule, 'A cake a day keeps cravings at bay'
 - A certain amount of trial and error may be needed to determine which foods you can or can't tolerate. Keeping a food and symptom diary for a short time will help you to identify culprits
 - Some people find that tonic water can help to relieve spasms
 - Seek advice from a doctor or qualified dietician if you follow a restrictive diet. For example, if you cut out dairy foods, you will need to ensure that you obtain calcium from other sources
 - Try to follow other general healthy lifestyle advice such as keeping your weight down and taking exercise

Getting equipped

A huge amount of specialist equipment is available to make life easier. It can be hard to accept that you need this type of help but try to regard these items in the same way as you would a washing-machine or dish-washer, ie a labour-saving device that is there to help you get the most out of life:



- There are numerous sources of advice and information. Try your local Council as a first port of call. They can be very helpful in terms of supplying information and assisting with adapting your home. Ask your local housing department whether a Care and Repair scheme operates in your area
- Find out whether there is a Mobility Centre or a Disability Living Centre in your area
- Occupational therapists can be a useful source of information and can provide practical advice on ways to adapt your home to make it easier to manage
- If you use a wheelchair, make sure it is suitable for your current needs. Don't put up with one that you were given years ago – your needs may well have changed and it is likely that new, easier to manage models may now be available

- Use gloves to protect your hands if you use a wheelchair. Cycle gloves are cheaper and last longer than wheelchair gloves
- Fix a holder for crutches or walking stick to your wheelchair so that they are on hand whenever you need them
- You may wish to consider a four-wheeled walker with a seat. They are portable, light and mean that you can always sit down wherever you are
- Install a shower seat if standing for long periods of time is a problem
- If getting in or out of the bath is a problem, get a bath board or bath seat to sit on
- Most equipment is standard rather than being custom-made to suit an individual's needs. REMAP is a charitable organisation which exists to provide bespoke aids for people with disabilities. They can adapt anything from wheelchairs and commodes to everyday items such as taps and hi-fis



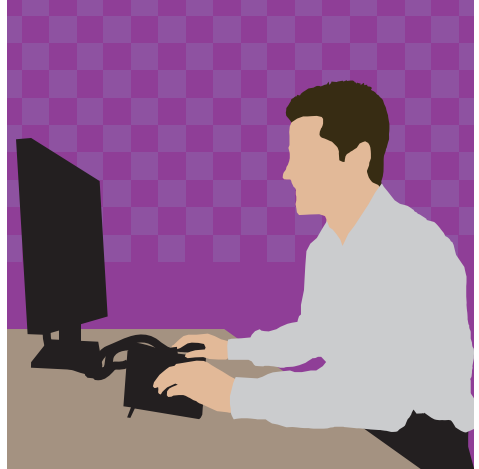
Educational needs

Having MS does not mean that you cannot pursue your studies, although you may need to adjust your plans to take account of your condition:

- Check on LEA funding in your area. Many part-time adult education courses are free for students receiving certain benefits
- Contact the Additional Needs department at your college. They can help with issues such as access, funding and special exam provision. They can also arrange an assessment for the Disabled Students' Allowance
- Disabled Students' Allowances are available on top of loans for degree study. These can be used for study-related costs such as special keyboards, cassette recorders, printers and additional travel costs
- There are special provisions for people with disabilities within the assessment for a student loan, for example if you need to pay for domestic help



- Investigate a range of universities/colleges to assess their attitude towards, and facilities for, students with disabilities – most are extremely positive
- Investigate the possibility of credit transfer, in which previous courses can be taken into account, even if you have suspended your studies or need to change to a more accessible venue
- If you are already studying, explain your situation to your tutors as soon as possible, particularly your personal tutor. This will help if you need to arrange coursework extensions or have to take time off for appointments or due to ill health
- The Open University can be a good choice for people with disabilities. It has a comprehensive website with a separate section for people with disabilities
- Whatever type of study you undertake, pace yourself and work around your MS. Try to study during your ‘best’ time of the day. If lectures/seminars take place at a time of day when you tend to feel particularly tired, see if someone can record them for you



Work, rest and play

For some people, MS impacts on virtually every aspect of their life, while for others it is very much 'business as normal'. However your MS affects you, make sure you make the most of your abilities:

- You don't necessarily need to give up work just because you have MS. Gather together as much information as possible to educate your employer and reassure them that you can continue to be an asset to the company
- Explore the possibility of working from home or cutting down your hours to part-time work
- If you have had to stop working and miss it, try something else such as voluntary work. Alternatively, keep busy with a leisure pursuit
- Remember the saying 'Use it or lose it'. Keep mobile, even if it only means getting out of bed and sitting in the garden each day - fresh air does wonders for depression
- Try not to sit still for long periods of time. If possible, stand up and have a walk round every so often, to prevent stiffness in your legs



- Take regular exercise if you are able. Swimming is a good option. Even if you are not a strong swimmer, spending time in warm water can be beneficial and relaxing
- Exercising with a friend can be fun and can help to keep you motivated
- If you are able to use a gym, consider investing in a few sessions with a personal trainer who can focus on your condition and devise exercises that suit your abilities
- Keep your mind active. Focus on anything that interests you, whether it is crosswords, books, knitting, crocheting or simply good conversation with friends
- Meet with friends as often as you can and chat about anything other than MS to keep your horizons open
- There are many holiday options for people with disabilities. RADAR and other organisations publish directories with details of accessible holiday accommodation
- If you depend on someone to look after you, you could consider respite care so that you can both have a break



Getting informed

When it comes to finding out about MS, everyone is different. Some people feel much more in control if they are fully informed while others prefer to gather information on a strictly 'need to know' basis:

- Not everyone wants to know everything about MS all at once – seek information when you feel ready to deal with it
- It is natural to fear the unknown. Learning about the processes involved in MS can help you to understand why you experience particular symptoms and allow you to make more informed decisions about treatment
- Do as much reading and research as you like but try to maintain a balanced view – MS takes many different forms so don't always think the worst
- Don't be fobbed off if people can't immediately provide the information you seek. If you want answers to questions or need specific support, be persistent



- Be prepared to do your own research and try and keep up to date with the latest findings. It is encouraging to see that progress is being made
- Contact as many MS organisations as you can – they all have something different to offer. Take advantage of courses for newly diagnosed people with MS, if available
- Other people with MS are often the best source of information and support. If you have access to the Internet, join a chatroom or forum. It can be really comforting to share notes and tips with somebody who is in the same situation and understands what you are going through
- MS nurses and therapy centres are also an excellent port of call for information and support
- Don't always assume that others know more about MS than you do. You may well end up educating your doctor about this condition. They deal with many different illnesses while you are a real expert in one!
- Make sure that those around you, including family and friends, have a good understanding of what MS is and what it means. This will help them to provide appropriate support when you need it

Useful contacts

The following organisations were all suggested by people who contributed tips and ideas

MS Organisations

MS Trust

provides information for anyone affected by MS, provides education for MS nurses and other health professionals and funds applied research
Spirella Building, Letchworth Garden City, SG6 4ET
01462 476700
info@mstrust.org.uk
www.mstrust.org.uk

MS Society

funds research, runs holiday homes and respite care, provides grants, education, information and training for people affected by MS
372 Edgware Road, London, NW2 6DT
Helpline - 0808 800 8000
info@mssociety.org.uk
www.mssociety.org.uk

MS Society Scotland National Office

Ratho Park, 88 Glasgow Road, Ratho Station, Newbridge, EH28 8PP
0131 335 4050 enquiries@mssocietyscotland.org.uk

MS Society Wales

Temple Court, Cathedral Road, Cardiff, CF11 9HA
02920 786676 mscymruwales@mssociety.org.uk

MS Society Northern Ireland

34 Annadale Avenue, Belfast, BT7 3JJ
02890 802802

National Federation of MS Therapy Centres

(England, Wales and Northern Ireland)

represents more than 70 self-help centres providing a wide range of drug-free symptom management therapies

info@ms-selfhelp.org

www.ms-selfhelp.org

Scottish Association of MS Therapy Centres

scotinfo@mstherapycentres.org.uk

www.mstherapycentres.org.uk

See also the Map of MS services

www.mstrust.org.uk/information/services/

MS Resource Centre

provides support and information and publishes New Pathways magazine

7 Peartree Business Centre, Peartree Road, Stanway,

Colchester, CO3 5JN

0800 783 0518

www.msrc.co.uk

Jooly's Joint

an online community of people who live with MS

www.mswebpals.org

MS International Federation

Includes links to national societies around the world and news of developments in MS research

www.msif.org.uk

Useful contacts

MS People UK Forum

an online community for people with MS, as well as for all friends, families and supporters

www.ms-people.com

MS People UK Discussion List

a discussion list is led by its members, whose experiences cover the spectrum of life with MS

www.mstrust.org.uk/interactive/mspeopleuk.jsp

Revive MS Support

operates an independent MS Therapy Centre in Glasgow and MS outreach clinics throughout the west of Scotland

The MS Centre, 16 Chapel Street Estate, Maryhill, Glasgow, G20 9BQ

0141 945 3344

info@revivemssupport.org.uk

www.revivemssupport.org.uk

Action MS

an independent organisation providing support to people with MS in Northern Ireland

Knockbracken Healthcare Park, Saintfield Road, Belfast, BT8 8BH

02890 790707

info@actionms.co.uk

www.actionms.co.uk

Other Useful Contacts

Benefits

Benefits Enquiry Line

confidential advice and information for people with disabilities, and their carers and representatives, on the range of benefits available and how to claim them

0800 88 22 00

Disability Alliance

provides information and advice about entitlement to benefits and services

Universal House, 88-94 Wentworth Street, London, E1 7SA

0207 247 8776

www.disabilityalliance.org

Citizens Advice (CAB)

offers free, confidential, impartial and independent advice, including debt and consumer issues, benefits, housing, legal matters and employment rights. Contact details of local CABs are available on the website or will be in the phone book

www.citizensadvice.org.uk

Useful contacts

Getting Around

Shopmobility

a federation of more than 250 schemes providing scooters and wheelchairs for shoppers with mobility problems

PO Box 6641, Christchurch, BH23 9DQ

08456 442 446

info@shopmobilityuk.org

www.shopmobilityuk.org

Motability

a national UK charity, which helps disabled people and their families to become more mobile

Motability Operations, City Gate House, 22 Southwark Bridge Road,
London, SE1 9HB

0845 456 4566

www.motability.co.uk

Forum of Mobility Centres

a network of independent organisations who offer information, advice and assessment to individuals who have a medical condition that may affect the ability to drive or use a motor vehicle

Providence Chapel, Warehorne, Ashford, TN26 2JX

0800 559 3636

mobility@rcht.cornwall.nhs.uk

www.mobility-centres.org.uk

Equipment and Adaptations

Disabled Living Foundation

provides information on disability equipment, day-to-day household gadgets, new technologies and training techniques

380 - 384 Harrow Road, London, W9 2HU

0845 130 9177

advice@dlf.org.uk

www.dlf.org.uk

Assist UK

formerly the Disabled Living Centres Council, Assist UK provides accurate, reliable and impartial information and advice about products and equipment for easier living through more than 40 local centres

Redbank House, 4 St Chads Street, Manchester, M8 8QA

0870 770 2866

general.info@assist-uk.org

www.assist-uk.org

Remap

federation of volunteer organisations that provide custom made aids for people with disabilities

0845 130 0456

www.remap.org.uk

Useful contacts

Demand

carries out and encourages the design and manufacture of equipment that improves the quality of life of people with a disability

The Old Chapel, Mallard Road, Abbots Langley, WD5 0GQ

01923 681800

info@demand.org.uk

www.demand.org.uk

AbilityNet

offers advice, support, assessment of needs, and the supply of adapted computer equipment, for people with any sort of disability

0800 269 545

enquiries@abilitynet.org.uk

www.abilitynet.org.uk

Foundations

has information on local Home Improvement Agencies (HIA). These organisations can offer help with finding funding and managing the work. In some areas, these agencies are called Care & Repair or Staying Put

Foundations, Bleaklow House, Howard Town Mill, Glossop, SK13 8HT

01457 891909

foundations@cel.co.uk

www.foundations.uk.com

Disability Organisations

RADAR

supports local and national disability organisations, campaigns for improvements in disabled people's lives and provides information to support independence and equality

12 City Forum, 250 City Road, London, EC1V 8AF

0207 250 3222

radar@radar.org.uk

www.radar.org.uk

Dial UK

network of 140 local disability information and advice services run by and for disabled people

St Catherine's, Tickhill Road, Doncaster, South Yorkshire, DN4 8QN

01302 310123

enquiries@dialuk.org.uk

www.dialuk.info

Disability, Pregnancy & Parenthood international

promotes better awareness and support for disabled people during pregnancy and as parents

National Centre for Disabled Parents, Unit F9, 89-93 Fonthill Road
London, N4 3JH

0800 018 4730

info@dppi.org.uk

www.dppi.org.uk

Useful contacts

Carers

Princess Royal Trust for Carers

provides information, support and practical help to carers through more than 100 independently-managed Carers Centres

www.carers.org

London Office

Unit 14, Bourne Court, Southend Road, Woodford Green, IG8 8HD

0844 800 4361

info@carers.org

Glasgow Office

Charles Oakley House, 125 West Regent Street, Glasgow, G2 2SD

0141 221 5066

infoscotland@carers.org

Northern Office

Suite 6, Oak House, High Street, Chorley, PR7 1DW

01257 234070

infochorley@carers.org

Wales Office

Victoria House, 250 Cowbridge Road East, Canton, Cardiff, CF5 1GZ

Tel: 02920 221788

infowales@carers.org

Crossroads Association

provides practical support to carers in the home and with respite care
10 Regent Place, Rugby, Warwickshire, CV21 2PN
0845 450 0350
communications@crossroads.org.uk
www.crossroads.org.uk

Carers UK

provides information and advice to carers
20/25 Glasshouse Yard, London, EC1A 4JT
020 7490 8818
info@ukcarers.org
www.carersonline.org.uk

Our thanks to everyone who submitted ideas and tips

The MS Trust would like to thank the Loughborough University Department of Information Science for their help in collecting the majority of these tips as part of the research they undertook to determine the information needs of people with MS.

The MS Trust is a charity working with and for the 85,000 people in the UK with multiple sclerosis (MS). Our vision is to enable people with MS to live their lives to the full.

We provide:

- information that is tailored to what people want to know
- education for health professionals about what people with MS need
- research into better management of MS
- support for anyone affected by MS



Multiple Sclerosis Trust
Spirella Building, Bridge Road
Letchworth Garden City
Hertfordshire SG6 4ET

T 01462 476700
E info@mstrust.org.uk
www.mstrust.org.uk

Registered charity no. 1088353