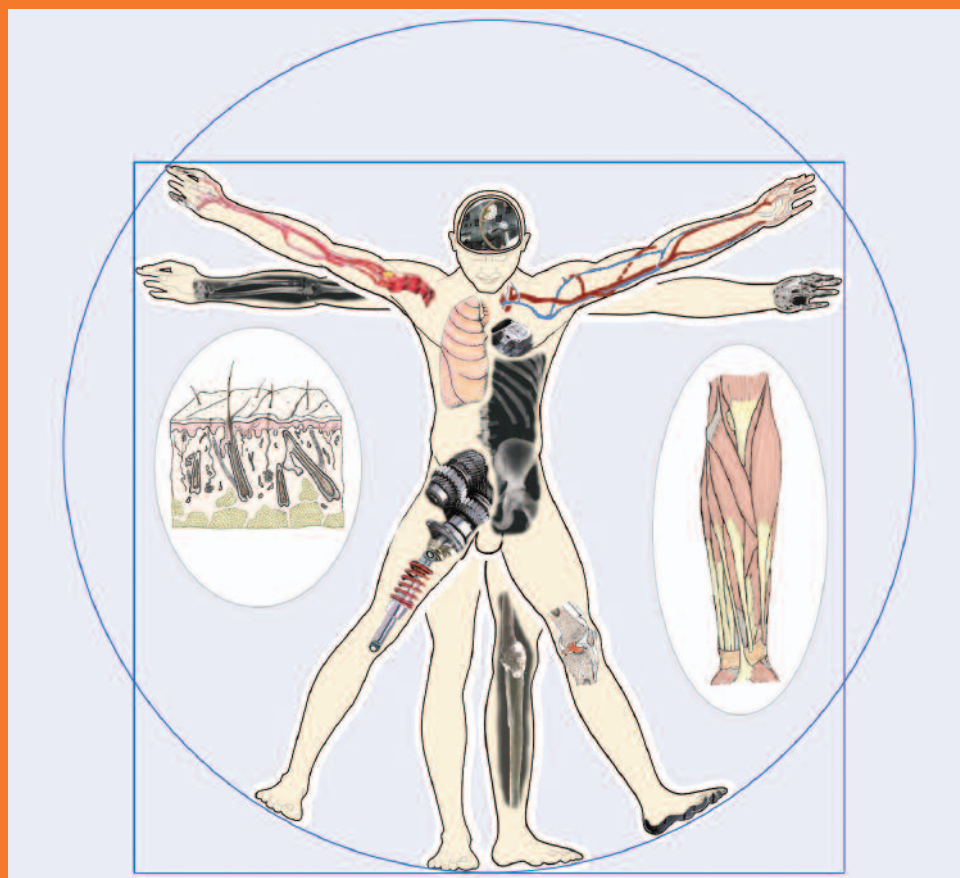


MS CARERS



The man's guide to caring for someone with multiple sclerosis

Haynes Owners Workshop Manual





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Telephone: 020 7922 7908

www.menshealthforum.org.uk

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Multiple Sclerosis Society

Multiple sclerosis (MS) is the most common disabling neurological condition affecting young adults, and we estimate that around 100,000 people in the UK have MS. MS is the result of damage to myelin – the protective sheath surrounding nerve fibres of the central nervous system. This damage interferes with messages between the brain and other parts of the body.

For some people, MS is characterised by periods of relapse and remission while, for others, it has a progressive pattern. For everyone, it makes life unpredictable.

The MS Society is the UK's largest charity dedicated to supporting everyone whose life is touched by MS. It provides respite care, a freephone MS helpline, grants for home adaptations and mobility aids, education and training, MS specialist nurses and a wide range of information. Local branches cater for people of all ages and interests and are run by people with direct experience of MS.

The MS Society also funds over 80 vital MS research projects in the UK. See page 16 for contact details.

The Multiple Sclerosis Society of Great Britain and Northern Ireland is a charity registered in England and Wales (207495) and Scotland (SC016433)

MS Carers

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ARE YOU A CARER?

Yes?

Then you are one of over six million people in the UK who provide practical or emotional support to someone close to them.

There are an estimated 100,000 people with MS in the UK and many of these people will be cared for by a family member at some time – perhaps temporarily during a relapse, perhaps on and off, or on a regular basis for many years.

You might never have considered yourself a carer, and it's not everyone's best wish for a title, but it acknowledges the huge amount of unpaid work that you do, and this recognition could open doors to support that's designed with carers in mind.

No two men will have exactly the same situation, but as a man caring for someone with multiple sclerosis (MS), you are not alone.

This manual can't cover everything you'll want to know, but it will highlight the support that's available for you and how you can get hold of it.



NOT ONLY A CARER

Being a carer is just one part of who you are.

Across the UK there are millions of men caring for partners, parents, children, siblings and close friends. Some are balancing paid work with their caring role; every carer tries to balance their caring with the other roles they take on in life – those of partner, father, brother, colleague or son.

A lot of carers feel uneasy at times about their changing role. It's not uncommon to be worried about the way relationships change, or the increasing number of tasks you might have to face.

Emotions change with changing times so

you might feel frustration, resentment, guilt, anger, fear, loneliness or depression. You could have feelings of loss and grief if your expectations and plans change.

They are common to most people but there is help available to stop them becoming an even bigger issue.

If you need a break, some financial or practical help, or a person to talk to about your concerns, let someone know.

As well as health and social services, a number of organisations exist to support you, some of which are listed at the back of this manual.

Get in touch and see how they can help.



CARING FOR SOMEONE WITH MS

MS affects people in many different ways. There are some common symptoms, including:

- fatigue
- bladder problems
- muscle stiffness
- vision problems

But not everyone gets the same symptoms and they can come and go without warning day to day, year to year. The care you give not only involves helping with daily activities, but also demands patience and understanding. MS can affect people's memory, thinking, moods and emotions, and so-called 'invisible symptoms', such as fatigue or pain, can make it harder to explain to others. These symptoms highlight the need to keep communicating with each other.

MS is a tricky one to describe

Just as you get to grips with one symptom, it can disappear, and perhaps resurface months or even years later.

Shifting goalposts

You and the person with MS will find ways to manage symptoms which work best for your situation, but with the shifting goalposts of MS it's also important to stay in touch with health and social care professionals for their expertise. You can also get information and support from the MS Society's free publications, website and Helpline (see page 16 of this manual).



TREATMENTS FOR MS



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Although there is no cure for MS, there are treatments which can bring relief from symptoms, which a GP, MS nurse or neurologist might prescribe. There are also therapies such as physiotherapy which a lot of people find helpful.

There are a number of drugs which can help some people reduce the amount of relapses they have – known as disease modifying drugs. Some people may also benefit from ‘immunosuppressant’ drugs, which reduce the activity of the immune system. For more

information on treatments that are available and research into new ones, get in touch with the MS Society.

An MS nurse can often be a useful central point to access the various health care services available. Sometimes a GP, district nurse or community matron can provide this help. For social services, you and the person you care for should both be registered with a social worker so you can access their services when you need to without unnecessary delay.

RELATIONSHIPS

Caring for a family member or close friend can affect that relationship but there is help at hand.

Many of us anticipate the possibility of caring for our parents when they become old and frail, but the reality of caring for a parent with MS, often before they reach old age, can be quite a shock. For some younger people with MS, it becomes necessary to move back to the parental home, to be cared for by parents who may have been anticipating a carefree retirement. For those who are parents, caring for an adult child with MS can become very physically

demanding, even without considering the emotional impact of seeing their once healthy child being affected by MS.

Whether sudden or gradual, changes within relationships brought about by caring can be difficult to cope with. Yet caring can also be extremely rewarding and fulfilling. Getting the right support for everyone can help make sure it continues to be so – this support could come from health and social services, carers groups and the MS Society, as well as friends or family.

Many couples worry about being a carer or being cared for. It can challenge a relationship in many ways.



Caring for your partner can raise many challenges

Caring can be a huge part of your relationship. Consider how your caring responsibilities are impacting on your relationship.

If for instance it is:

- inhibiting how you talk to each other,
- inhibiting how you show affection to each other, or
- preventing a satisfying sexual relationship.

It might be useful to see if social services can arrange additional support for your caring tasks, particularly for any tasks that you might find distressing, perhaps for things such as helping them go to the toilet.

Contact the MS Society for the free publications *Living with the effects of MS* and *Sex, intimacy and relationships*. Call 020 8438 0799 (weekdays 9am-4pm), or download from www.mssociety.org.uk/publications.

As the saying goes, 'it's good to talk' – with each other, and with trained professionals. Many people going through relationship changes find counselling sessions beneficial – including people who were sceptical at first. A GP or MS nurse might be able to refer you, or you could contact an organisation such as Relate (see back page).



CARING FOR YOURSELF AS WELL

If you are concentrating on the well-being of someone else it's sometimes easy to overlook your own health. But looking after your own physical and emotional health benefits both you and the person you care for.

Caring can be tiring physically, emotionally and mentally, and the pressures of caring can creep up on you. Small issues can add up to a bigger problem if they are ignored. Back pain, muscle aches, stress or anxiety, for example, can all get worse if you leave them to bubble away under the surface, so speak to your GP sooner rather than later, and see what support social services can offer.

Caring with confidence

Many carers find it useful to learn about different aspects of caring through local groups, at home with workbooks or online. Resources like these can help with managing finances, keeping healthy and finding time for your own needs. 'Caring with Confidence' (www.caringwithconfidence.net) is a large scheme offering this kind of support in many parts of England. But wherever you are in the UK, ask your GP or local carers' group for details of what's available.



GETTING SOME HELP

Sometimes it is not possible or practical to carry on doing all the care yourself. Asking for help is not a sign that you are shirking from caring – it can help you be a more effective carer.

Many carers benefit from the support of paid care workers who come in for a few hours to help out. A little help for you could make a difference for you both.

Speak to other carers (on carers' courses, or at local carers' groups, for example) and voluntary organisations such as the MS Society, Princess Royal Trust for Carers or Carers UK. Exactly what's available may vary from area to area, but practical, financial and emotional support is available.



PRACTICAL SUPPORT AND THE CARER'S ASSESSMENT

Many hands

You might decide you can benefit from practical help, perhaps a few hours a week where a second person comes in to lend a hand with certain tasks. This could give you time to do other things or make some jobs easier and safer, such as helping someone to change position, or get in and out of bed.

The first step is to contact your local social services and ask for a Carer's Assessment. This looks at *your* situation as a carer and is in addition to, not instead of, their assessment of the person with MS. The assessment will involve an occupational therapist visiting your home.

You have the right to an assessment if you care for someone for 'a substantial amount of time on a regular basis'. If you are refused an assessment, you can ask them for reasons in writing and a local carers' group or Citizens Advice Bureau can offer advice.

A Carer's Assessment will identify extra support that can be provided to help you. Carers' services are often free of charge, but whether there is a charge or not, knowing what might be available locally can make a big difference.

Other practical help, such as home adaptations, will be considered as part of the assessment of needs for the person with MS. Your Carer's Assessment can be carried out separately or alongside this.

Social services will often cover some, if not all, of the cost of smaller adaptations and gadgets. For example, to help with the physical impact of moving and lifting, or to allow someone to carry on doing things for themselves where they can. Grants are available for more involved work.

Contact the MS Society for the free publication *Adaptations and your home*. Call 020 8438 0799, weekdays 9am-4pm, or download it from www.mssociety.org.uk/publications.

GETTING HELP IN A HURRY



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With all the planning in the world, surprises can still happen and you might need more help in a hurry (if you fall ill, for example).

It's a good plan to get a Carer's Assessment as soon as you can, so you are on the books of social services in the event of an emergency. Ask them what the procedure would be if there was an emergency, and who you should contact. Some areas

have 'emergency alert cards' which register who you would want to contact and what you would want to happen in an emergency. To find out about the MS Society Carer's Emergency card, contact Welbeing (who run the scheme) on freephone 0800 085 8344.

Knowing that plans could be put in place if there was an emergency can bring valuable piece of mind.

RECHARGE YOUR BATTERIES – RESPITE CARE

Don't feel guilty about feeling worn out. Many people's relationships benefit from the occasional break from caring and being cared for.

Getting a break from caring can be physically and emotionally valuable for you and the person you care for. For some, a week's respite break in a dedicated respite care

centre may be best. For others, a few hours break on a regular basis may be more useful.

Your Carer's Assessment will help identify what respite (often called 'short breaks') you can be offered. You should also be offered support to arrange the breaks – to help find a suitable agency or respite care home, for example.

The MS Society has a directory of respite care homes: www.mssociety.org.uk/respite or call 020 8438 0799.



FINANCIAL HELP

Unclaimed help

Many carers are eligible for benefits to help with the costs of caring, but £740 million of carers' benefits is left unclaimed each year. This is money set aside to help you, so make sure you get what you are entitled to.

The benefits system is complicated, but there are organisations to help you find out what you're entitled to and help you claim, including Citizens Advice, the Benefit

Enquiry Line, the MS Society and local carers' groups.

If you are not in full-time employment, you may be able to claim Carer's Allowance, but there are many other benefits which could be worth looking into. Carers UK have information about this and other benefits: www.carersuk.org.

If social services cannot meet the full costs of services, such as home adaptations or respite care, the MS Society Grants Team can discuss with you possible sources of grants. Email grants@mssociety.org.uk or call 020 8438 0700 (0131 335 4050 in Scotland).



KEEP IN TOUCH – SOCIAL NETWORKS

It's all too easy to become isolated. It's another thing which can creep up unexpectedly, especially if you are spending a lot of time caring. Isolation can add to stress or feeling low and we all need the chance to see other people and socialise.

Getting practical help from a paid care worker even for just a couple of hours a week might be one way of finding time for you to stay in touch with friends.

There might be activities you and the person with MS can do together with others, such as events organised by local MS Society branches.

If it's tricky to get out of the house together, paid carers might be able to accompany you both when you go out to make that possible. Your Carer's Assessment should take account of your needs for access to employment, education and leisure.

Even if you don't feel able to get to get out of the house for social events, carers' organisations have telephone support and online chat rooms and message boards – a chance to chat to other carers about life, the universe and everything... Take a look at the carers' message board at www.mssociety.org.uk/chat.



WORKING AND CARING

Not every carer wants or is able to continue working. But if you do, employers have a legal duty to consider some flexibility, and social services should allow for work or training in your Carer's Assessment.

Since 6 April 2007, you have a legal right to ask your employer for flexible working if you are caring for someone who is a relative or lives at the same address as you.

The websites www.direct.gov.uk and www.nhs.uk/carersdirect have details of your rights and the support available if you want to stay in work. You can also call Carers Direct on 0808 802 0202.

If you are considering going back into education or employment, you may be able to get help from the MS Society towards course fees or other costs. Email grants@mssociety.org.uk or call 020 8438 0700 (0131 335 4050 in Scotland).

CARING SKILLS – TRAINING FOR CARERS

As a carer, you may be developing a whole range of skills that are very new to you. You might want to get training in certain aspects of caring, such as lifting without hurting your back or how to manage particular treatments such as catheters. This can boost your confidence and reassure you that you are doing them in the easiest, safest way.

MS nurses or district nurses will often show you how to manage new treatments, but local carers' centres also run courses for

dealing with stress, lifting and handling and advice for older carers. You can find your nearest carers' centre through social services, or by contacting Carers UK or the Princess Royal Trust for Carers (see the back page of this booklet).

The MS Society has two free factsheets which might be helpful: *Posture and movement 1 - an introduction* and *Posture and movement 2 – moving well with MS*. Go to www.mssociety.org.uk/carers or call 020 8438 0799 (weekdays 9am-4pm).

FURTHER INFORMATION

MS Society

Membership is open to people with MS, their families, carers, friends and supporters. You can help the work of the MS Society by:

- becoming a member
- making a donation
- offering your time as a volunteer

Contact us

MS National Centre
372 Edgware Road
London NW2 6ND
Telephone 020 8438 0700

MS Society Scotland
National Office
Ratho Park
88 Glasgow Road, Ratho Station
Newbridge EH28 8PP
Telephone 0131 335 4050

MS Society Northern Ireland
The Resource Centre
34 Annadale Avenue
Belfast BT7 3JJ
Telephone 028 90 802 802

MS Society Cymru
Temple Court
Cathedral Road
Cardiff CF11 9HA
Telephone 029 2078 6676

Freephone MS Helpline

The MS Society Helpline offers confidential information and emotional support to anyone with MS, carers, family or friends. Available in 150 different languages by speaking to a Helpline worker via an interpreter. Call 0808 800 8000 (Monday to Friday, 9am-9pm) or e-mail helpline@mssociety.org.uk

Website

You can keep up to date with news relating to MS with the MS Society website where there are also message boards including one specifically for carers.

www.mssociety.org.uk

Free publications

Specifically for carers:

- *Caring for someone with MS: a handbook for family and friends*
- *MS in your life – a guide for young carers*

These are available free of charge, along with a wide range of other publications to help manage the symptoms and effects of living with MS. Some information is available in other languages, including Urdu, Turkish, Farsi and Welsh.

Telephone 020 8438 0799
(weekdays, 9am-4pm)
www.mssociety.org.uk/publications

Join us

Members of the MS Society receive the bi-monthly magazine, *MS Matters*, with lifestyle articles and the latest information on research, treatments and news.

Telephone 020 8438 0759
www.mssociety.org.uk

Grants Team

Telephone 020 8438 0700
(0131 335 4050 in Scotland)
Email grants@mssociety.org.uk

Carers' message board

www.mssociety.org.uk/chat

Other carers' books

- *Looking after someone: a guide to carers' rights and benefits*

Free booklet produced by Carers UK (see below).

- *Selfish Pig's Guide to Caring*

By Hugh Marriott. Publisher: Little Brown Book Group (Published 1 May 2006)

Language: English. ISBN: 978-0751537093

Other organisations

Carers UK – Carers UK is a national organisation representing unpaid carers. It campaigns on behalf of carers and also provides a range of information services. It can help you find local information services and has a directory of national and local services who can help. They also run CarersLine (see below). www.carersuk.org

CarersLine – CarersLine is Carers UK's advice line, offering information on benefits and social services. It's free and confidential. Open Wednesday and Thursday each week from 10am to 12pm and 2pm to 4pm.

Telephone 0808 808 7777

Carers Connect – social networking website for carers.

www.carersconnect.com

Relate/Relationships Scotland – Both offer advice, relationship counselling and sex therapy.

Telephone 0300 100 1234

(0845 119 2020 in Scotland)

www.relate.org.uk

(www.relationships-scotland.org.uk in Scotland)

Princess Royal Trust for Carers – The Princess Royal Trust for Carers is the largest provider of comprehensive carers support services in the UK. The Trust has a network of 144 independently managed Carers' Centres and interactive websites, as well as information on all aspects of caring.

Telephone 0844 800 4361. www.carers.org

Citizens Advice – Local offices are listed in the telephone directory and on their websites:

England and Wales: www.citizensadvice.org.uk

Scotland: www.cas.org.uk

Northern Ireland: www.citizensadvice.co.uk

Online advice: www.adviceguide.org.uk

Government services

For information on all aspects of health and social services, visit www.direct.gov.uk

Contacting social services

You can find them online or listed under 'social services' in the phone book. Social services should be able to give you information on the services they provide as well as other carer resources in the area.

Contacting health services

To find a health care service near you, ask a care professional for a referral, or contact:

England – Telephone 0845 46 47

www.nhsdirect.nhs.uk

Wales – Telephone 0845 46 47

www.wales.nhs.uk

Scotland – Telephone 08454 24 24 24

www.nhs24.com

Northern Ireland – Telephone 028 9032 4431

www.healthandcareni.co.uk

Benefits Enquiry Line

General advice or information about benefits. Lines are open between 8.30am and 6.30pm Monday to Friday and between 9am and 1pm on Saturdays.

Telephone 0800 88 22 00

Textphone 0800 24 33 55

Carer's Allowance Unit

The Carer's Allowance Unit can send you a claim form or answer questions about carer's allowance.

Telephone 0845 608 4321

Caring for someone

This website has information on money matters, employment and carers' rights.

www.direct.gov.uk/en/CaringForSomeone

Malehealth

the first choice for men's health info

Malehealth, the MHF's health information website for men, has had over three million visitors in the last two years. Why? Because it's fast, it's free and it's independent. Penises to prostates, alcohol to ageing, lungs to livers, hearts to hormones – whatever your question on male health, you'll find the answer at

www.malehealth.co.uk

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