

# MS Essentials

For people living with MS

This publication is available in large print (22 point)  
Call 020 8438 0799 or email [infoteam@mssociety.org.uk](mailto:infoteam@mssociety.org.uk)

## Support and planning ahead – for people severely affected by MS

The information in this booklet is for people with multiple sclerosis (MS) who are managing many ongoing or severe symptoms, and who have high levels of disability. This information might also be helpful for families, friends and carers.

This booklet talks about the role of ‘holistic’ palliative care for managing MS at different times, as well as ways to plan for the future. It doesn’t go into detail about managing different symptoms such as muscle spasms, pain or cognitive changes. If you’d like more information on those topics, get in touch with our UK Information Team.

The information in this booklet sometimes covers sensitive areas, which some people may find upsetting. It looks at very personal issues which can be difficult – emotionally and practically – for everyone involved, including families, carers, friends and care professionals.

If you want to speak to someone about the issues raised here, you can call the MS Society Helpline. This freephone Helpline is there for anyone affected by MS. Call 0808 800 8000 weekdays 9am-9pm.

### Contents

- 02 Quality of life
- 03 Get the support you need
- 04 Health care services
- 05 Social care services
- 06 Palliative care for MS
- 07 Long-term residential care
- 08 Financial assistance
- 08 Planning for the future
- 15 End-of-life care
- 16 Further information

### If you help look after someone with MS...

If you are a family member or friend helping look after someone with MS, you might also want to read *Caring for someone with MS: a handbook for family and friends*. Younger family members might be interested in *MS in your life – a guide for young carers* and [www.youngms.org.uk](http://www.youngms.org.uk)

Where you see this symbol , there are other organisations which might be helpful. Their details are in the ‘Useful organisations’ section of this booklet (page 19).

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## Quality of life

Everyone looks for ways to improve the quality of their life, and has different ideas about how to do this. MS symptoms might change your approach to improving the quality of your life, but you'll probably still be considering things like social activities, interests and new experiences. You might find it helpful to:

- Stay in touch

Don't lose contact with friends, colleagues and social groups completely, even if it's hard to keep up with things like you used to.

- Join a local group

Remember that there will be other people with limited mobility or different needs affecting their choices. You might find there's already a social group or club in the area that suits you such as an MS Society branch. These may be advertised in local libraries, through local carers' centres, and online.

- Get online

If getting somewhere is difficult, social networking sites and the possibilities of the web might be a good alternative.

- Facebook, Twitter and the MS Society message boards are all ways to stay in touch and make contact with huge numbers of people (or just a few if you prefer!).

- A service like Skype offers free video calling so you can chat with friends and family face to face over the internet.

Internet access could be easier if you get helpful changes made to the computer software or hardware. For example, voice recognition software saves typing and using a mouse. Ask organisations like Abilitynet, the ITCH Network, Momentum (in Scotland) and independent living centres for advice. 

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Never been online? You're not alone, and your local authority might know about beginners' courses in your area.

Or find out more from a great online beginners guide – [www.bbc.co.uk/webwise](http://www.bbc.co.uk/webwise)

The MS Society Grants Team might be able to help with a grant for a computer – 020 8438 0700. In Scotland, call 0131 335 4050.

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- Join or start up a book club

Get together with friends to discuss things you've all read or listened to – you might meet at home, in a café or bar, or even online.

- Try something new

There are often alternative ways of doing something you enjoy. For example, if you love reading but it's tiring to turn the pages, you might try audio books, or electronic books (to read on a computer, a smart phone or a tablet such as the iPad or Kindle). Electronic books can often be played as audio books as well.

## A change of scenery

The effects of MS might sometimes make having a day out feel like an impossible challenge. But careful planning and appropriate care can make this possible, even if you have a lot of difficulties.

You might want a day out with the family, a holiday with a friend or a short break where care is provided. Direct payments or a personal budget for social care services might cover the costs. Depending on your savings or income, you might need to contribute towards the cost. There's more information about support from social care services on page 5.

The local MS Society branch should know what's available locally, or what others have found in a similar situation. You can also contact the MS Society Information Team for more details (see page 16). For options in Scotland, contact the national office in Edinburgh (see back page).

A break from the normal routine gives everyone involved a boost. With recharged batteries, it's often easier to face the challenges of MS.

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## Get the support you need

The right support from social and health care services can make a huge difference – whether you have MS or you help look after someone with MS. The right financial support is also important, so it's worth making sure you're getting any financial assistance you are entitled to.

## Choices about care

There will be choices to make about the care you get, such as who provides it, when and where. Make sure you and others involved understand these choices. Don't be afraid to ask care professionals to explain things again if they are not clear, or to give information in writing so you can read it and discuss it later.

## Personalised support

Social care (and to some extent health care) is moving towards a 'personalised' approach. This means you have more freedom to choose what support you get. You might hear about direct payments, personal budgets, individual health budgets, and 'self-directed support'. These are all schemes either already in use or being tried out in pilot areas. Speak to your local authority, GP or MS nurse about what's on offer where you live – and how it might help you.

The MS Society has more information about personalisation check online or contact the Information Team. [i](#)

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## Health care services

Anyone with MS could see a number of different health care professionals, in addition to their GP. These include:

- neurologists
- MS nurses
- neuro-physiotherapists
- occupational therapists
- speech and language therapists
- wheelchair therapists
- other members of the rehabilitation team
- dietitians

A GP can refer you to any of these different services, or you might be put in touch through another health care professional.

You might be referred to a 'multi-disciplinary team'. This team involves professionals with different areas of expertise, working together. One member of the team may be your main point of contact to coordinate care. Often, this is an MS nurse, but not always, so check you know your team coordinator or 'case manager' and how best to get in contact with them.

Sometimes it might feel overwhelming to have so many people involved. But different care professionals can help manage the various symptoms of MS, avoid complications (such as pressure ulcers) and help with the wellbeing of everyone involved.

The MS Society booklet *Getting the best from health care services* has more information about getting the health care services you need, and how to complain if you feel you are not.

There are guidelines and standards for the care you can expect. Some of the key documents are listed in 'Further information' (page 16).

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## Social care services

Social care services (social work, in Scotland) can provide equipment and adaptations to the home, personal care services to help with daily activities, day care, short respite breaks, or residential care.

Their contact details should be listed in the local telephone directory, or your doctor's surgery should have them. The websites [www.direct.gov.uk](http://www.direct.gov.uk) and [www.nidirect.gov.uk](http://www.nidirect.gov.uk) list local authority contact details.

People with MS and family or friends who help look after them can ask for a 'needs assessment' ('care needs assessment' in Scotland). This is the first step to getting support which can make a real difference to everyday life.

Family carers can ask for a 'carer's assessment'. This assessment is your opportunity to discuss with social services what help and support you may need to make caring easier for you.

If circumstances change, or you feel you need more or different support, you can ask for your needs to be reviewed.

Read more in the MS Society booklets *Getting the best from social care services*, *Getting the best from social care services in Wales* and *Getting the best from social work in Scotland*.

### Blurred boundaries – is it health or social care?

The boundaries between what comes under health care and what comes under social care services can be confusing – and could have an impact on what you are asked to pay towards services.

Health care is generally free. Social care is usually means tested (meaning that you pay something if you have more than a certain amount of savings or income).

If someone has complex and unpredictable care needs, health services might contribute towards the costs of providing nursing care that's needed. This can become particularly significant if you are arranging long-term residential care.

The process and the possible outcomes vary between the nations of the UK. But you might find some, or even all, of the care costs are covered by the NHS. Read more about paying for nursing care in the MS Society booklet *Residential care and your options*.

# Palliative care for MS

People used to only think of ‘palliative care’ as a part of cancer care, but increasingly, it’s also recognised that it can be helpful for people with other conditions, including MS. Palliative care aims to maximise someone’s quality of life during the advanced stage of an illness.<sup>1,2</sup>

It has also often been seen as only for people near the end of their lives. In fact, with a long-term condition such as MS, it can help at other times of life too.

Palliative care supports people to have the best possible quality of life by considering all the needs that a person might have. This could be by managing any symptoms that cannot be cured, but might respond to treatment to some degree. And, importantly, by taking into account psychological, spiritual and family needs.

There will of course be an impact on families and friends during this time and it is important to know what help is available to you locally that will help support everyone involved. Local carers’ services can offer support and information. Contact social care services or the Princess Royal Trust for Carers for details of local support.

For a person with MS, palliative care might include pain relief, the management of swallowing difficulties, or prevention of pressure ulcers. It could also involve supporting the person to plan ahead and make the most of life – finding ways to enjoy activities of interest and maintain relationships. Many health and social care professionals take a palliative care approach to helping people with MS. Sometimes, specialist palliative care professionals might advise them on how best to manage overall care.

Access to specialist palliative care may vary depending on what services are available where you live. But wherever you are, you need a ‘specialist palliative care assessment’ to access these services. A GP, MS nurse or other health or social care professional should be able to make a referral for this. In some areas, you might be able to refer yourself for this assessment.

Your Primary Care Trust (England), Health Board (Scotland and Wales) or Health and Social Care Trust (Northern Ireland) should have the contact details for a community palliative care team who can carry out the assessment. Or you might ask to see a palliative care specialist at hospital, perhaps on the same day you see your neurologist.

In Scotland, the Scottish Partnership for Palliative Care website has details of services in each Health Board area. [!\[\]\(e1d6102fe77919492c04879c8450f1f5\_img.jpg\)](#)

## Hospices

Many community palliative care teams work closely with a hospice – a residential setting for palliative care. People may be admitted to a hospice for symptom control or terminal care. Many hospices also offer day care facilities.

Through the hospice you might be able to access complementary therapies and physiotherapy, even if you don't stay there.

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For more about hospices, including finding a service in your area, contact Help the Hospices. [i](#)

The National Council for Palliative Care website has more detailed definitions of palliative care, and describes what makes a 'Gold Standard' palliative care service. [i](#)

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## Long-term residential care

There may come a time when long-term residential care, either on a temporary or permanent basis, is the most appropriate option.

It can be very difficult and distressing for all involved to come to decisions around this. It helps a great deal to have appropriate information to hand – and to know that you have considered all the options for support at home as well as residential care.

Social care services should explain the options to you, and involve health care professionals.

The MS Society booklet *Residential care and your options* looks at many of the issues – including finding a suitable care home and assessing the quality of their services. It also has guidance on meeting the costs, both in terms of planning ahead and meeting immediate needs.

If you help look after someone with MS, you might also want to get in touch with organisations such as Carers UK and the Princess Royal Trust for Carers. They have information and links to local groups who might have been through similar circumstances. [i](#)

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## Financial assistance

MS can have a financial impact. Check that you are getting the benefits you are entitled to. Your social worker, Citizens Advice Bureau or local benefits agency can help. Our booklet *Benefits and MS* has more information.

If you have complex and unpredictable symptoms you may be entitled to nursing care provided by the NHS, which might reduce what you need to pay for care. See page 5 'Blurred boundaries – is it health or social care?'

You might also be able to get grants for certain aspects of life with MS. This could include grants for computers so you can get online, or to help you arrange a short break. Grants are available from a number of sources for different kinds of items and activities. The MS Society Grants Team has information and might be able to provide grants directly – [www.mssociety.org.uk/grants](http://www.mssociety.org.uk/grants), [grants@mssociety.org.uk](mailto:grants@mssociety.org.uk) or call 020 8438 0700. In Scotland, call 0131 335 4050.

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## Planning for the future

Everyone wants to make choices about their life now and in the future. Because there might be times when MS makes it difficult to express your wishes, planning ahead can be very useful.

### What kind of plans?

Many people want to think about the kind of care and treatments they would want in different circumstances, and how their finances should be handled. We look at some of the legal documents to help do this – and the idea of 'mental capacity' – later in the chapter.

Planning ahead can also be about the things, small and large, that make up everyday life – making sure people around you now and in the future know about the music you like, important religious or political beliefs, or how you like your hair. What we like and don't like, what we believe, and how we like to be treated day to day – these are important for a good quality of life. A 'Statement of wishes and preferences' can help you record these things clearly (see page 10).

Remember that your thoughts and feelings could change and you might want to revisit documents from time to time, to be sure they still represent your views.

Before making any firm plans, it's a good idea to:

- Involve family, friends or carers in discussions. They might be the people who can pass on the information most easily. They will also be greatly affected by the choices you make.

- Speak with a health care professional who knows you (perhaps an MS nurse).
- Involve a solicitor. When recording your wishes formally, to make sure things are clear and ‘legally correct’.
- Make sure that your GP knows your plans and that they record them in your medical records. You should also make sure social care services have a record, and they are available for hospital visits.

## What kind of plans?

You might already have made your wishes for future care known to family or friends, or to care professionals. You may not have discussed the topic at all – it’s often not an easy conversation to begin. [i](#)

### Read more about planning ahead

The National Council for Palliative Care has written a booklet you might find helpful when thinking about all this – *Planning for your future care – a guide*. They also have a range of leaflets called Dying Matters – let’s talk about it. These look at ways to discuss the issues you need to talk about to get the most from life. The series includes leaflets for information for family and friends.

## Mental capacity

‘Mental capacity’ refers to a person’s ability to make decisions – your ‘capacity’ to make choices for your care, lifestyle and finances.

There are some specific laws that say how to decide if someone has capacity to make decisions, and how someone’s affairs should be managed if they lose that capacity. In England and Wales, this is the Mental Capacity Act (2005). In Scotland, the Adults with Incapacity (Scotland) Act 2000 applies. These laws both assume that someone has capacity unless it is shown otherwise.

In Northern Ireland, at the moment there is no specific law for mental capacity. New legislation is not expected until 2013.

Wherever you live in the UK, you can plan ahead for the possibility of losing capacity – by setting up a ‘power of attorney’, as we explain (on page 10). [i](#)

## More about the UK laws on mental capacity

For England and Wales, a guide to the Mental Capacity Act is available from the Office of the Public Guardian. [i](#)

For Scotland, the Office of the Public Guardian (Scotland) has information about the Adults with Incapacity (Scotland) Act. And the Scottish Government publishes *Adults with Incapacity (Scotland) 2000. A short guide to the Act.* [i](#)

For more on the law in Northern Ireland, see the Northern Ireland Executive website. If you don't have access to a computer, call the UK Information Team on 020 8438 0799 or the MS Society Northern Ireland on 028 9080 2802.

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## Statement of wishes and preferences

A statement of wishes and preferences can cover areas of life that are not included in a power of attorney or advance decision to refuse treatment.

You might use one of these statements to explain your feelings, beliefs and values. If you can't express these in future, this can help the people caring for you to make the right choices on your behalf.

They are sometimes referred to as 'personal statements' or 'advance statements of wishes and preferences'.\*

A statement of wishes and preferences is not legally binding, but care professionals must take into account what you say in the statement. It only applies if you can't make these decisions at the time you need the care.

You can write down the statement or make a sound recording of you speaking it. You could even simply tell your wishes to family and carers, but writing or recording it is a better way to be sure your views are heard.

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\* In Scotland, a 'personal statement' is not the same as an 'advance statement'. An 'advance statement' in Scotland comes under the Mental Health Act and specifically applies to treatments for a mental health issue.

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## Power of attorney

A power of attorney is a way of planning ahead so that your wishes are respected, if at some time you cannot express those wishes.

When you set up a power of attorney, you choose people you trust to look after your affairs. This includes making decisions and acting on your behalf. It is only used if you can no longer do these things yourself. It's a sort of insurance – you might never need it, but if you do, it's a vital way to get your wishes heard.

In England and Wales, the documents you complete are called Lasting Power of Attorney (LPA). There are two types of LPA that you might want to make. In one, you write down your wishes for your 'health and welfare'. The other covers 'property and financial affairs'.

In Scotland, documents called a Welfare Power of Attorney and a Continuing Power of Attorney work in a similar way.

In Northern Ireland, you can set up an Enduring Power of Attorney. This only covers financial matters, not personal care arrangements.

The attorneys you appoint can only act on the power of attorney after it is registered with the Office of the Public Guardian (or the Office of Care and Protection, in Northern Ireland). [i](#)

### More about making a power of attorney

For England and Wales, the Office of the Public Guardian has a series of guides on Lasting Power of Attorney.

For Scotland, the Office of the Public Guardian (Scotland) has a series of guides on Power of Attorney.

For Northern Ireland, the Office of Care and Protection website has a leaflet on Enduring Power of Attorney. Citizens Advice also has information. If you don't have access to a computer, call the UK Information Team on 020 8438 0799 or the MS Society Northern Ireland on 028 9080 2802.

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## Advance decision to refuse treatment

As the name suggests, an 'advance decision to refuse treatment' lets you record in advance your wish to refuse specific treatments in specific circumstances.

Like a power of attorney, an advance decision to refuse treatment (ADRT) would only apply if there comes a time when you can't make or communicate your decision. [i](#)

## A good example of planning for care

### **Ruth was 63 years old. She had secondary progressive MS, with many complications.**

Ruth had very limited physical ability and could only use aids and assistive technology controlled by her mouth. She experienced frequent chest infections and developed a serious infection which needed hospital treatment.

When she was admitted to hospital, Ruth was fatigued and breathless. She couldn't communicate her wishes effectively. Her condition got worse and it was recommended that she needed artificial ventilation or she would die. However, the health care professionals at first felt that ongoing ventilation might not be in her best interests and not what she would have wanted. They asked for a palliative care assessment.

The palliative care consultant had a full and frank discussion with Ruth's husband and it was clear that Ruth had expressed a firm desire to have all life-prolonging measures. She considered herself to have a good quality of life and wished to 'be around to boss her husband for a little longer'. Ruth was ventilated for a few days and made a good recovery.

When Ruth was discharged from hospital, she was referred to the community palliative care team. They made regular home visits.

Over the next couple of years, Ruth continued to have frequent chest infections. On her third admission to hospital for this she decided to have only oral antibiotic treatment and not to be ventilated if it was thought to be needed.

On her fourth admission she took up the offer to move to the local hospice which had links with her palliative care team. Here, they took the time to discuss end-of-life issues with her.

After a couple of weeks, Ruth went home from the hospice. When she had a further chest infection, Ruth died peacefully at home while using antibiotics for symptom management.

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In England and Wales, a valid ADRT is legally binding on a health care professional. ADRTs are covered by the Mental Capacity Act, so health care professionals must act according to your wishes. However, the ADRT cannot direct anyone to do something illegal. It cannot, therefore, be an instruction to actively shorten life – euthanasia and assisted suicide are illegal in every nation in the UK.

In Scotland and Northern Ireland, an ADRT does not have the same legal standing – ADRTs are not covered by the Adults with Incapacity (Scotland) Act 2000, and there is no equivalent law in Northern Ireland yet. However, your wishes in the ADRT should be taken into account by medical professionals. And if they are ignored, it might be considered illegal under existing law.

## Examples of treatments covered in an advance decision to refuse treatment

**These are a few of the more common treatments and circumstances people consider when they set up an ADRT. They are key decisions about care which most people would want to be in control of, even if they can't express their wishes at the time.**

### **Artificial feeding**

Sometimes people cannot take or swallow food or drink safely and it becomes necessary to consider using a feeding tube.

Before deciding on this, the benefits have to be weighed against the inevitable major change and possible complications. Benefits include maintaining hydration, weight and skin condition (which is important for preventing pressure ulcers), and being more mentally alert. But the procedure to insert the tube and the support needed to manage it once in place are significant, including making sure feeding is safe. Ongoing support is needed for everyone involved.

The fact that the procedure might prolong life also needs to be considered. Everyone has their own view on how they want to live and what's most important to them. You might feel that prolonging life with artificial feeding is a benefit or a downside – depending on the exact circumstances and your own views. It is not a decision to be made lightly and should be done only after discussions that include health care professionals, family and carers. The pros and cons need to be weighed up to make an informed decision.

### **Artificial ventilation**

At some point you might need to discuss issues around artificial ventilation.

MS can cause swallowing difficulties and make it harder to cough. This can make people prone to more frequent and more severe chest infections such as pneumonia.<sup>3</sup>

Health care professionals should clearly explain the risks of chest infection and possible treatment options.

If you know all the options, you can make decisions about the treatments you might want. For example, you might want only oral antibiotics and/ or physiotherapy. Or you might want intravenous antibiotics and/ or physiotherapy proceeding (if needed) to tracheostomy and artificial ventilation (sometimes referred to as 'life support').

You might want to have different treatments in different situations, so make sure that is clear in your wishes.

These are huge decisions to make and you need to have all the information and discuss all the possible implications so that you can make an informed decision.

### **Cardiopulmonary resuscitation – CPR**

Medical guidelines and the law protect anyone's right to be resuscitated if the procedure is reasonably likely to be successful, and if it's likely there will be a reasonably good prognosis following resuscitation.<sup>4,5</sup>

Because of this, and medical staff's duty of care, it is likely that people very severely affected by MS will be asked about their views on resuscitation within hours of being admitted to hospital.

This is likely to be a stressful time in any case, so it is often good to have considered the question beforehand.

It's something to discuss with family, and with carers, key workers and health and social care professionals who know you. This way, decisions can be carefully considered, and friends and family can be consulted.

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Some key points to remember:

- If you make an ADRT, remember that your wishes might be different in different circumstances. For example, would you choose a different treatment option if you were involved in an accident and you were otherwise relatively well?
- You should review it regularly after you've made it. Make sure you still agree with it.
- Make sure that everyone involved in your care is aware of it and where the document is kept. Make sure your GP has a copy and a copy is held in your hospital records.

### **More about advance decisions to refuse treatment**

For England and Wales, there is a comprehensive NHS website with information – [www.adrtnhs.co.uk](http://www.adrtnhs.co.uk). The Motor Neurone Disease Association also has a useful factsheet.

For Scotland, the Motor Neurone Disease Association Scotland has a useful factsheet. NHS Scotland publishes the booklet, *Decisions about cardiopulmonary resuscitation – Information for patients, their relatives and carers*.

For Northern Ireland, all these resources might be useful general guides, despite advance decisions to refuse treatment not being covered by a specific.

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## End-of-life care

Care and support is important at every stage of life. It makes sense to let people know your wishes for the end of life just as you would at other times. This way you can stay in control of the care you receive.

End-of-life care is often not an easy thing to talk about. But discussion and planning in advance can be helpful (see Planning for the future, page 8). The National Council for Palliative Care's campaign, 'Dying Matters' has several small leaflets which could be helpful. They look at ways to start the conversation with people about end-of-life care and planning ahead, whether you are thinking about your own care, or that of a loved one. 

Decisions about care and support at the end of life will need to involve:

- the person with MS, or any documents that express their wishes if they can't express them now
- family
- friends
- carers
- health and social care professionals involved in the care of the person with MS

Care teams that include palliative care specialists – as well as hospice, district or MS nurses, carers and GPs – can help manage symptoms in the last days of life. Your GP, MS nurse or district nurse can explain what the different options are in your area – although if you have lived with MS for some years, you might already know many of the professionals involved in your palliative care.

Accessing appropriate specialised care can provide comfort at the end of life – at hospital or hospice, in residential care or at home. This care should also help those closest to you at a very difficult time.

# Further information

UK Information Team  
020 8438 0799  
infoteam@mssociety.org.uk  
National offices  
– see back cover  
www.mssociety.org.uk

## Read more

Our free booklets help explain MS, look at its practical and emotional effects, and help you find your own ways to manage life with MS. Titles are available in large print, audio format and a number of languages.

We can help you find and borrow other books, research articles and DVDs about living with MS. Search online or call the UK Information Team.

## Find out more online

Get the latest on research, campaigns and MS news. Chat online with our message boards and Facebook. Follow us on Twitter, see the MS community at Flickr and watch us on YouTube.

Children and teenagers can find out more and link up through our YoungMS site: [www.youngms.org.uk](http://www.youngms.org.uk)

## Join us

Receive local and national magazines and newsletters, and get involved locally and nationally. Be as involved as you like. Just by being a member you strengthen the voice of all people with MS, and help us continue our vital work. Join online, or call 020 8438 0759 or your national office.

## Get in touch

The freephone MS Helpline offers confidential emotional support and information for anyone affected by MS, including family, friends and carers. Information is available in over 150 languages through an interpreter service. **0808 800 8000 (weekdays 9am-9pm)** or [helpline@mssociety.org.uk](mailto:helpline@mssociety.org.uk)

Contact the UK Information Team or your national office if you have any questions about MS.

## Near you

Our volunteers run over 300 local branches and support groups. They provide information about MS and local services, and a chance to meet others affected by MS and take part in a range of activities.

In many parts of the country, you can pick up our booklets at MS Society Info Points. Larger information centres – including ones in our national offices in London, Belfast, Cardiff and Edinburgh (Newbridge) – can help you with information about MS and services in your area.

Or come along to our local and national events and learn more about MS from expert care professionals, researchers and other people with the condition. Find out more online or call your national office.

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## Further reading

### Legislation and guidelines

There are several pieces of legislation and guidelines used to plan and improve care, palliative care and end-of-life care for MS.

You might find it useful to know what services you can expect. Some standards and regulations are decided on locally, so ask locally for this information.

See Useful organisations for contact details of the publishers listed below.

### UK

*NICE Clinical Guideline 8. Multiple Sclerosis: management of multiple sclerosis in primary and secondary care.* Published by National Institute for Health and Clinical Excellence (2003).

### England

National End of Life Care Programme.  
[www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk)

This NHS programme works with health and social care services across all sectors in England to improve end of life care for adults – by implementing the Department of Health’s End of Life Care Strategy (see below). The website has a wealth of information used by professionals to deliver end-of-life care.

*End of Life Care Strategy. Promoting high quality care for all adults at the end of life.* Published by Department of Health (2008).

*National Service Framework for Long-term Conditions.* Published by Department of Health (2005).

### Scotland

*Living and Dying Well: A national action plan for palliative and end of life care in Scotland.* Published by The Scottish Government (2008) and *Living and Dying Well: Building on Progress* (2010).

*Better Health, Better Care Action Plan.* Published by The Scottish Government (2007).

*Neurological Health Services Clinical Standards.* Published by NHS Quality Improvement Scotland (2009).

*Clinical Standards – Specialist Palliative Care.* Published by the Clinical Standards Board for Scotland (2002) and available from NHS Quality Improvement Scotland.

*Making Good Care Better.* Published by the Scottish Government and the Scottish Partnership for Palliative Care (2006).

## **Wales**

*Designed for Life*. Published by the Welsh Government (2005).

*A strategic direction for Palliative Care Services in Wales*.  
Published by the Welsh Government (2003).

## **Northern Ireland**

*Palliative and End of Life Care Strategy for Northern Ireland – consultation document*. This consultation document was published by the Department of Health, Social Services and Public Safety in December 2009.

*A Healthier Future – A Twenty Year Vision for Health and Wellbeing in Northern Ireland 2005–2025*. Published by Department of Health, Social Services and Public Safety (2004).

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## Useful organisations

Organisations are listed alphabetically. The letters in the margin indicate the nations where they operate.

**E** England

**NI** Northern Ireland

**S** Scotland

**W** Wales

**UK** Whole of the UK

### **E NI W Abilitynet**

Helping disabled people use computers and the internet – information about adaptations and helpful software.

Telephone 0800 269 545

Textphone 01926 312847

[www.abilitynet.org.uk](http://www.abilitynet.org.uk)

### **UK Age Cymru, Age Northern Ireland, Age Scotland, Age UK**

Charity which produces a number of factsheets including Hospital Discharge Arrangements.

England

Telephone 0800 169 6565

[www.ageuk.org.uk](http://www.ageuk.org.uk)

Northern Ireland

Telephone 0808 808 7575

[www.ageuk.org.uk/northern-ireland](http://www.ageuk.org.uk/northern-ireland)

Scotland

Telephone 0845 125 9732

[www.agescotland.org.uk](http://www.agescotland.org.uk)

Wales

Telephone 0800 169 6565

[www.ageuk.org.uk/cymru](http://www.ageuk.org.uk/cymru)

### **UK Carers Northern Ireland, Carers Scotland, Carers UK, Carers Wales**

Information and support for people helping look after a loved one.

England

Telephone 0808 808 7777

(Wednesday and Thursday 10am-12pm and 2pm-4pm)

[www.carersuk.org](http://www.carersuk.org)

Northern Ireland

Telephone 028 9043 9843

[www.carersni.org](http://www.carersni.org)

Scotland  
Telephone 0808 808 7777  
(Wednesday and Thursday 10am-12pm and 2pm-4pm)  
[www.carerscotland.org](http://www.carerscotland.org)

Wales  
Telephone 0808 808 7777  
(Wednesday and Thursday 10am-12pm and 2pm-4pm)  
[www.carerswales.org](http://www.carerswales.org)

### **UK Citizens Advice**

Help with welfare rights, housing and disability advice. Your local office (known as a 'bureau') is listed in the telephone directory and on their website.

To find local offices in England and Wales [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

In Scotland [www.cas.org.uk](http://www.cas.org.uk)

In Northern Ireland [www.citizensadvice.co.uk](http://www.citizensadvice.co.uk)

Online advice [www.adviceguide.org.uk](http://www.adviceguide.org.uk)

### **W Community Health Councils**

Offers help if you have questions, problems or complaints about NHS services. The contacts below can provide details of your local Council.

Telephone 0845 644 7814  
[www.communityhealthcouncils.org.uk](http://www.communityhealthcouncils.org.uk)

### **UK Compassion in Dying**

For more information on advance decisions to refuse treatment.

Telephone 020 7479 7731  
[www.compassionindying.org.uk](http://www.compassionindying.org.uk)

### **ESW Crossroads Care**

Support for family and friends who provide care and support.

England and Wales  
Telephone 0845 450 0350  
[www.crossroads.org.uk](http://www.crossroads.org.uk)

Scotland  
Telephone 0141 353 6504  
Email [carerssupportline@crossroads-scotland.co.uk](mailto:carerssupportline@crossroads-scotland.co.uk)

### **UK Cruse Bereavement Care**

Offers free bereavement support, advice and information, across the UK.

England and Wales  
Telephone 0844 477 9400  
[www.crusebereavementcare.org.uk](http://www.crusebereavementcare.org.uk)

Northern Ireland  
Telephone 028 9079 2419  
[www.cruseni.org](http://www.cruseni.org)

Scotland  
Telephone 0845 600 2227  
[www.crusescotland.org.uk](http://www.crusescotland.org.uk)

### **UK Disabled Living Foundation**

Offers advice and information on equipment and assistive technology for independent living.

Telephone 0845 130 9177 (Monday to Friday, 10am-4pm)  
[www.dlf.org.uk](http://www.dlf.org.uk)

### **UK Dying Matters**

Set up by the National Council for Palliative Care, Dying Matters is a group of organisations working to promote public awareness of dying, death and bereavement. The website includes helpful leaflets to download in the 'Resources' section (see 'Action packs and tools').

Telephone 020 7697 1520  
[www.dyingmatters.org](http://www.dyingmatters.org)

### **W Healthcare Inspectorate Wales**

Inspects health care services. If you have complaints about social care services that have not been resolved by the care providers, you can contact the Inspectorate to take it further.

Telephone 029 2092 8850  
[www.hiw.org.uk](http://www.hiw.org.uk)

### **NI Health and Social Care in Northern Ireland**

A gateway website to health and social care services, including Health Trusts, GP surgeries and Health Boards.

[www.hscni.net](http://www.hscni.net)

### **S Health Rights Information Scotland**

Produces information about patients' health rights and about the health services. It cannot advise on individual circumstances.

Telephone 0141 226 5261  
[www.hris.org.uk](http://www.hris.org.uk)

## **UK Help the Hospices**

A national charity with information about hospices and palliative care services around the UK and Ireland.

Telephone 020 7520 8200  
[www.helpthehospices.org.uk](http://www.helpthehospices.org.uk)

## **S Independent Advice and Support Service (IASS)**

IASS offers free, confidential, independent and impartial advice. It supports patients, their carers and families in their dealings with the NHS and in other matters affecting their health. There are IASS caseworkers in every Health Board in Scotland who deal with concerns and complaints about any NHS service.

To find your nearest IASS caseworker, visit Citizens Advice Scotland at [www.cas.org.uk](http://www.cas.org.uk) or look up your local Citizens Advice Bureau in the phone book.

## **E Independent Complaints Advocacy Service (ICAS)**

Supports patients and their carers wishing to pursue a complaint about their NHS treatment or care. They are divided into a number of regions.

To find your local office, see the Citizens Advice site [www.adviceguide.org.uk](http://www.adviceguide.org.uk) or ask your hospital or GP surgery.

## **ESW Independent living centres**

The National Centre for Independent Living lists local independent living centres in England, Wales and Scotland. These centres might have information about computer adaptations, accessible software and even details of local beginners' courses in using the internet.

Telephone 0845 026 4748  
[www.ncil.org.uk](http://www.ncil.org.uk)

## **UK ITCH network**

The IT Can Help network offers advice and support to get you started using computers. ITCH works with Abilitynet.

Telephone 0800 269545 (ask for an IT Can Help volunteer).  
[www.itcanhelp.org.uk](http://www.itcanhelp.org.uk)

## **S Mental Welfare Commission for Scotland**

Offers information on mental capacity issues.

Telephone 0800 389 6809  
[www.mwscot.org.uk](http://www.mwscot.org.uk)

### **S Momentum**

In Scotland, their 'Adapt and assist' programme can help you gain confidence using computers. They also have information about adaptations and software that can make computers easier to use.

Telephone 0141 952 6494  
[www.momentumsotland.org](http://www.momentumsotland.org)

### **E W Motor Neurone Disease Association**

Publishes a useful factsheet about advance decisions to refuse treatment in England and Wales.

Telephone 08457 62 62 62  
[www.mndassociation.org](http://www.mndassociation.org)

### **S Motor Neurone Disease Scotland**

Publishes a useful factsheet about Care Planning and End-of-Life Issues: Advance Directives.

Telephone 0141 945 1077  
[www.mndscotland.org](http://www.mndscotland.org)

### **UK National Council for Palliative Care**

Promotes good palliative care for all who need it. Can supply directories of local palliative care services. They have information on the Mental Capacity Act 2005.

England, Northern Ireland and Wales  
Telephone 020 7697 1520  
[www.ncpc.org.uk](http://www.ncpc.org.uk)

Scotland (Scottish Partnership for Palliative Care)  
Telephone 0131 229 0538  
[www.palliativecarescotland.org.uk](http://www.palliativecarescotland.org.uk)

### **UK National Institute for Health and Clinical Excellence (NICE)**

Assesses treatments on the NHS. Publishes the NICE guidelines for MS listed on page 25.

Telephone 0845 003 7780  
[www.nice.org.uk](http://www.nice.org.uk)

### **NI Patient and Client Council**

Offers help if you have a problem or complaint with NHS services. The Council's headquarters can give local contact details.

Telephone 0800 917 0222  
[www.patientclientcouncil.hscni.net](http://www.patientclientcouncil.hscni.net)

### **E W Patients Association**

Has guidance on writing advance decisions and statements.

Helpline 0845 6084455

[www.patients-association.org.uk](http://www.patients-association.org.uk)

### **UK Patient UK**

Online information about health care, including information about consent.

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

### **UK Princess Royal Trust for Carers**

Information and support for carers. Includes listings of local carer groups across the UK.

[www.carers.org](http://www.carers.org)

England and Northern Ireland

Telephone 0844 800 4361

Scotland

Telephone 0141 221 5066

Wales

Telephone 02920 221 788

## **NHS**

### **E NHS Choices**

Online aid to making choices about your health, including contact details for health care services.

[www.nhs.uk](http://www.nhs.uk)

### **E W NHS Direct**

Online and telephone service offering health information. Also links to NHS Choices information for finding health care services.

Telephone 0845 4647

[www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk)

### **S NHS inform**

Scotland's national health information service with information on support groups and other general information. Find your nearest GP, dentist or other health service and information on wide scope of health related issues.

Telephone 0800 22 44 88 (8am-10pm every day)

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

## **S NHS Quality Improvement Scotland (QIS)**

This special health board advises, supports and assesses NHS boards – to help improve the quality of health care in Scotland. In 2009, QIS published Neurological Health Services Clinical Standards. These set standards for MS and other neurological services in Scotland. Each health board in Scotland has to implement these standards in the coming years. In some areas, services might already meet the standards.

Download the standards from [www.nhshealthquality.org](http://www.nhshealthquality.org) (search 'neurological health services').

## **S NHS Scotland**

Publishes the booklet, *Decisions about cardiopulmonary resuscitation – Information for patients, their relatives and carers.*

Telephone 08457 741 741  
[www.scotland.gov.uk](http://www.scotland.gov.uk)

## **S NHS 24**

Online and telephone service offering health information.

Telephone 08454 24 24 24  
[www.nhs24.com](http://www.nhs24.com)

For queries about health care which are not symptom or condition related, such as finding your nearest GP or dentist, ring **NHS inform**.

## **Government departments**

### **E Department of Health**

Publishes policy and guidance.

Telephone 0300 123 1002  
[www.dh.gov.uk](http://www.dh.gov.uk)

### **W Department of Health and Social Services (Wales)**

Provides information on health and social care in Wales, including contact details for local organisations, legislation and Welsh Government guidance.

Telephone 0845 010 3300  
Email [health.enquiries@wales.gsi.gov.uk](mailto:health.enquiries@wales.gsi.gov.uk)  
[www.wales.gov.uk/health](http://www.wales.gov.uk/health)

**NI Department of Health, Social Services and Public Safety**

Publishes policy and guidance including A healthier future.

[www.dhsspsni.gov.uk](http://www.dhsspsni.gov.uk)

**NI Department of Justice (Northern Ireland)**

Government site with information about the law in Northern Ireland.

Telephone 028 90 763000

[www.dojni.gov.uk](http://www.dojni.gov.uk)

**NI Northern Ireland Executive**

The Northern Ireland government website includes information about mental capacity law.

[www.northernireland.gov.uk](http://www.northernireland.gov.uk)

**NI Office of Care and Protection**

For Northern Ireland, this government site includes information about Enduring Power of Attorney. See also Citizens Advice.

Telephone 028 9072 4733

[www.courtsni.gov.uk](http://www.courtsni.gov.uk)

**E W Office of the Public Guardian**

For England and Wales, this government site includes information about Lasting Powers of Attorney and the Mental Capacity Act.

Telephone 0300 456 0300

Textphone 020 7664 7755

[www.publicguardian.gov.uk](http://www.publicguardian.gov.uk)

**S Office of the Public Guardian (Scotland)**

This government site includes information about Powers of Attorney and the mental capacity law.

Telephone 01324 678 300

[www.publicguardian-scotland.gov.uk](http://www.publicguardian-scotland.gov.uk)

**S Scottish Government**

Provides information on health and community care in Scotland, including copies of legislation and information for the public. Publishes Adults with Incapacity (Scotland) 2000. A short guide to the Act.

Telephone 0131 556 8400 or 08457 741741

[www.scotland.gov.uk/Topics/Health](http://www.scotland.gov.uk/Topics/Health)

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## References

Find these references at [www.mssociety.org.uk/library](http://www.mssociety.org.uk/library) or call the UK Information Team on 020 8438 0799. There may be a charge for the full article.

- 1 European MS Platform (2006) *Palliative care among people severely affected with multiple sclerosis*. Brussels, EMSP. ([www.ms-in-europe.com/w3p\\_dokumentarchiv/5palliativecare08.pdf](http://www.ms-in-europe.com/w3p_dokumentarchiv/5palliativecare08.pdf)).
- 2 Edmonds, P. *et al.* (2010) Palliative care for people severely affected by multiple sclerosis: evaluation of a novel palliative care service. *Multiple sclerosis*, 16(5), 627-36.
- 3 Compston, A. *et al.* (2006) *McAlpine's Multiple Sclerosis*, Elsevier, pp. 720-1.
- 4 British Medical Association, Resuscitation Council (UK) and Royal College of Nursing (2007). *Decisions relating to cardiopulmonary resuscitation. A joint statement from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing*. Accessed online November 2010 at [www.resus.org.uk/pages/dnar.pdf](http://www.resus.org.uk/pages/dnar.pdf)
- 5 UK (1998) Human Rights Act 1998, London, HMSO.

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Disclaimer: We have made every effort to ensure that information in this publication is correct. We do not accept liability for any errors or omissions, and policy and practice may change. Be sure to seek advice from sources listed.

Suggestions for improvement in future editions are welcomed. Please send them to [infoteam@mssociety.org.uk](mailto:infoteam@mssociety.org.uk)

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This title will be reviewed within two years of publication.

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## MS Society

Multiple sclerosis (MS) is the most common disabling neurological disorder 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. We provide a freephone MS Helpline; grants for home adaptations, respite care and mobility aids, education and training, support for specialist MS 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 around 80 vital MS research projects in the UK.

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 information

MS National Centre  
372 Edgware Road  
London NW2 6ND  
Telephone 020 8438 0700  
[info@mssociety.org.uk](mailto:info@mssociety.org.uk)

MS Society Scotland  
National Office, Ratho Park  
88 Glasgow Road  
Ratho Station  
Newbridge EH28 8PP  
Telephone 0131 335 4050  
[msscotland@mssociety.org.uk](mailto:msscotland@mssociety.org.uk)

MS Society Northern Ireland  
The Resource Centre  
34 Annadale Avenue  
Belfast BT7 3JJ  
Telephone 028 9080 2802  
[information@mssociety.org.uk](mailto:information@mssociety.org.uk)

MS Society Cymru  
Temple Court  
Cathedral Road  
Cardiff CF11 9HA  
Telephone 029 2078 6676  
[msscymru@mssociety.org.uk](mailto:msscymru@mssociety.org.uk)

National MS Helpline  
Freephone 0808 800 8000  
(weekdays 9am-9pm)  
[www.mssociety.org.uk](http://www.mssociety.org.uk)

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