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MS Essentials

For people living with MS

Support for people severely affected by MS

Approximately 10-15 per cent of people with MS become severely affected by the condition, and live with high levels of disability and many complex symptoms.

This publication seeks to answer the kinds of questions and concerns that people living with severe MS may have. These questions may include: What kinds of complex symptoms are associated with severe MS? What care and support is available? What can I do to plan for the future treatment and care? How can I ensure my wishes are respected? What is palliative care and is it appropriate for people with MS? You may also have questions about the very end of life.

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You may find some information in this publication upsetting. Facing these emotional, sensitive and highly personal issues is difficult for everyone involved, including families, carers and friends. You may wish to seek support from counselling services or specialist helplines when dealing with them now and in the future.

What is severe MS?

'People are generally considered to be severely affected by MS if mobility is very limited and many complex symptoms are experienced, meaning a significant amount of care and support is required from others.'

While life expectancy of people with MS is on average only slightly lower than that of the rest of the population, some people will find their MS progresses more rapidly causing greater disability and many complex symptoms. This more rapid progression of MS can be a result of either primary or secondary progressive MS. However, it is a minority of people – approximately 10 to 15 per cent – who become severely affected in the long-term.

People are generally considered to be severely affected by MS if mobility is very limited and many complex symptoms are experienced, meaning they become dependant upon others for care and support.

There is also an extremely rare and very aggressive form of MS, sometimes referred to as 'Marburg MS', which is associated with rapidly increasing disability. Only a few cases are seen and little is known about this condition, though research continues.

Others may find that they become temporarily severely affected by MS. This may be due to a very serious relapse leading to a sudden increase in disability and complex symptoms to manage. For example, a person may find that bladder problems are causing multiple urinary tract infections or they may experience repeated bouts of pneumonia, either of which can result in repeated hospital stays. When this happens, major life changes may be required and this can be extremely difficult for all involved.

In any of these situations MS may take over a person's life, affecting almost every action, from eating a meal to going outside.¹ It is therefore vital that care and support needs are catered for, appropriate services are accessed and equipment to aid independence is provided.

Types of symptoms experienced by people severely affected by MS

- Pain and sensory changes
- Bladder and bowel problems (for example, incontinence, urinary tract infections and constipation)
- Limited mobility and weakness (upper body and legs)
- Muscle spasms and stiffness
- Speech and swallowing problems
- Tremor
- Cognitive problems such as difficulties with memory and thinking
- Depression, mood swings and emotional problems
- Pressure sores

Each of these symptoms may be experienced by anyone with MS at any stage. What marks severe MS is that a person experiences many, or even most, of these symptoms simultaneously.

For more information about any of these symptoms, please contact the MS Society and ask for symptom specific publications.

Managing complex symptoms

'The MS Society has publications on each of the MS symptoms – please request copies if you want more information.'

It really helps if health care for people severely affected by MS can be coordinated by a multi-disciplinary neurological rehabilitation team. The different specialists will help ensure complex symptoms associated with severe MS are managed well and will work at preventing complications.

There are, however, some people faced with serious health conditions who feel that how they live their lives becomes taken over by health and social care systems. Some report that they feel they have lost their freedom to choose how they are cared for. If you are finding this to be the case, it can be a great help to have information about the different options. This allows informed decisions to be made.

Some people choose to use complementary and alternative approaches to health and well being either in addition to, or in instead of, conventional approaches. This publication focuses mainly on conventional health and social care systems, for more information on *Complementary and alternative medicine*, see MS Society publication dedicated to this subject.

Pain

Pain relief and pain management are a major aspect of good health care services. Pain affects around half of people with MS, and different management techniques need to be used for different types of MS pain. Pain may however be caused by something unrelated to a person's MS, and therefore appropriate assessment by a health care professional is vital.

- Musculoskeletal pain

Musculoskeletal pain describes the pain in muscles and joints. It can be caused by a lack of mobility in combination with muscle weakness, spasticity, walking problems and poor sitting posture, and can be made worse by the loss of protective muscle support due to weight loss or stiffness. Drugs, occupational therapy and physiotherapy can help treat this kind of pain, and some people also report that certain complementary therapies help them feel better.

- Neuropathic pain

Neuropathic pain, or nerve pain, is often described as feeling like burning or electricity shooting through an area of the body. People often also describe altered sensations or feelings, for example, feelings like 'insects crawling over the skin'. This pain results from nerve damage, and can be treated with drugs such as Amitriptyline, Gabapentin or Pregabalin,² and non-drug methods such as transcutaneous electrical nerve stimulation (also known as 'TENS'). Others report that acupuncture can bring relief.

Pressure ulcers

Pressure ulcers (also known as pressure sores or bed sores) can occur where there is continuous pressure on parts of the body that take weight. For example, the buttocks, heels and sides of ankles. These are known as 'pressure areas'. Factors such as immobility, incontinence, poor nutrition, lack of sensation or limited circulation can all put someone at risk of developing pressure sores. Assessment and help from specialists such as tissue viability experts, physiotherapists, district nurses and occupational therapists may help prevent these. They may provide pressure-relieving aids such as cushions and mattresses and also advice on lifestyle changes that may help.

Spasticity, muscle cramps and spasms

People severely affected by MS often experience muscle cramps, stiffness, spasms and spasticity. This can have a major impact on day-to-day life, and can increase fatigue and immobility. Appropriate specialists, such as neuro-rehabilitation consultants, occupational therapists and physiotherapists, can help manage these symptoms.

Spasticity varies from one person to another, so treatments need to be tailored to the needs of each person. Spasticity can also be associated with spasms, often in lower limbs. These can be triggered by touch or movement, are often extremely painful and may be worse at night.³ Measures such as improved positioning can help, but most people find medication becomes essential. Drugs that are effective at controlling muscle spasm include Baclofen, Diazepam, Dantrolene and Tizanidine.⁴ All these drugs have been shown to cause drowsiness and weakness. Other treatments include botulinum toxin injections (sometimes known as 'botox') into the affected muscles, or baclofen pumps. Sativex is an oral spray containing a cannabis extract which can be used in the relief of spasticity and other symptoms in some people. It is not widely available in the UK and it is the GP's decision whether to prescribe it. More information can be found on the MS Society's website or by calling the information team. There may also come a time when limbs become so weak they are not used, yet the spasticity is causing intolerable pain. In these cases phenol injections are sometimes used. This makes limbs go limp, and pain free.

It should also be noted that spasticity can be made worse by an untreated infection or acute constipation. These potential causes of a worsening of symptoms should be investigated before any increase is made to drug doses.

'The MS Society has publications on each of the MS symptoms – please request copies if you want more information.'

Cognitive problems – memory and thinking

Many people with severe MS find they experience problems with their memory and thinking – these difficulties are often referred to as ‘cognitive’ problems. Types of problems can include: difficulties recalling information; difficulties with mental speed such as being able to maintain the thread of things; problems evaluating or planning; and an inability to find words.

There are few treatments for cognitive problems, though neuropsychological rehabilitation and cognitive behaviour therapy can sometimes help.

Mood, depression and emotions

Many people with severe MS experience depression. There are also various other emotional symptoms including mood swings and emotional upheavals like bouts of anger or hyper-sensitivity where people become very emotional very easily and find it difficult to stop. In rare instances people also experience uncontrollable laughing and crying. In addition to this, there are behavioural changes that some people with severe MS experience. People may lose control over impulses, lack insight into situations or find it difficult to use initiative. Many of these symptoms can be successfully treated using drugs and sometimes talking therapies. Psychologists, MS nurses and palliative experts are all experienced in providing help for these problems. See page 20 for a definition of palliative care.

Swallowing

People severely affected by MS often find it difficult to chew and swallow food. This can result in problems with swallowing saliva causing it to leak from the mouth, and, in turn, causing soreness and discomfort in and around the mouth. If untreated swallowing difficulties can cause further problems as liquid may trickle into the airways and lungs, which in turn can cause pneumonia and chest infections. Specialists including speech therapists, dietitians, and occupational therapists, have extensive experience of dealing with these symptoms, and can help identify appropriate treatment and management options. These may include adapting posture when eating, or making alterations to the types of food eaten and eating style, and thickening liquids. In some cases, artificial feeding may be required either in addition to, or as a substitute, for regular eating. For more information on artificial feeding, see the MS Society publication, *Diet and nutrition*.

Bladder problems

Many people severely affected by MS experience bladder problems. These problems can include incontinence (not being able to control when the bladder is emptied) and difficulties properly emptying the bladder fully. Such problems can result in urinary tract infections. These can become quite serious for people severely affected by MS, particularly where they have gone unnoticed initially. Infections are treated using antibiotics, and people who experience bladder problems can find the expertise of continence nurses extremely helpful. They can help with managing the initial problem, as well as advise on how further complications may be prevented.

Constipation and nausea

Bowel problems in the advanced stages of MS are common. Constipation is the result of poor gut movement, and may be made worse by poor dietary intake, limited mobility and decreased intake of fluid for fear of urinary incontinence. Continence specialists and palliative care teams have extensive experience of managing constipation and can help identify what is causing the problem.

People may also experience nausea. This is often made worse by the reduced intake of fluids which can make the kidneys work less efficiently and lead to further nausea. Again, palliative care specialists can help minimise these problems.

Quality of life

People who are severely affected by MS, often say that their quality of life is compromised significantly. Families, carers and friends can also find that stresses and frustrations increase. This can however be minimised if everyone makes an effort to ensure that quality of life is maintained for all.

Quality of life of people severely affected by MS

Having a good quality of life is important for everyone. However, people often say that when they are dependant on others for care, life becomes increasingly isolated and hobbies and interests are sidelined. This need not be the case. It is important that social networks and interests are maintained. People may also find new interests and social networks are developed that better suit their changing lifestyle. These may be different to when a person was less affected by MS, though they can still be tailored to personal tastes and interests.

For example, if you once enjoyed reading and now find it tiring and difficult to turn pages, you may wish to listen to audio books. You may also find that some friends also enjoy reading and that you can arrange a book club where you can discuss books you have all read and enjoyed. Perhaps this could be done at your home, at a specially arranged time, or over the phone. Alternatively, a film or music club could be arranged where you watch videos or DVDs together with friends and can discuss them afterwards. Others find that there are whole new areas of interest they can explore. For example, today there are many adaptations that can be made to computers and other assistive technologies that can help make hobbies easier – independent living centres and other organisations like AbilityNet and the ITCH network can advise. Details can be found at the back of this booklet.

You may also find days out enjoyable. While this may require much practical planning, there are sometimes local organisations that offer such activities and give both you and your carer a break. Day care centres also often provide activities, as well as opening up new social networks, while also providing care on site. Your local MS Society branch should be able to advise on what is available in your area.

Being cared for can also impact upon relationships with partners, children and friends, as the dynamics change. This often occurs as you become more dependant on those you are close to for support. And, in marriages people sometimes say that these changing dynamics can make it hard to maintain a romantic relationship. Parents also sometimes find it hard when they turn to their children for help in meeting daily needs. For all these reasons it is important to make sure everyone is getting the support they need from all external services possible. If necessary, ask for your care plan to be reviewed and remember these services are an entitlement – not a favour.

Looking after your social life can also keep you connected to relationships outside your immediate family and carers, as well as helping to prevent feelings of isolation and depression.

Carers' quality of life

Carers' quality of life also matters. While many family members and friends find it easy to adjust to caring, others find the responsibility produces some physical stresses and emotional strains. Physical stresses may result from helping to transfer the person cared for, looking after intimate daily needs and lack of sleep. Emotional strains can result from the changing relationships and the sorrow of watching a loved one lose physical and emotional ability.

On top of the responsibilities of caring, there are additional day-to-day tasks, and possibly full or part-time employment. This can all result in carers feeling like there is little time left for other family members, seeing friends or participating in other social activities and hobbies. This can be frustrating and often leave carers feeling like there is little time to re-energise. It is therefore important carers all have all the support available and are encouraged to look after themselves too. Carers' well-being will depend on good physical and emotional health. Hobbies, social activities and getting a break from caring tasks are all important in maintaining quality of life. Some carers find they can get a break whilst external help is available from either health or social services. Alternatively, time spent at a local day care facility can give carers time to catch up on other routine tasks. Others find longer breaks provided by respite care invaluable. See the MS Society publications *The carers handbook* and *MS in your life – a guide for young carers*.

Planning for the future

'Everybody has the right to make choices about the care they receive now and in the future.'

MS symptoms require complex care and management. Everyone with MS has the right to make choices about the care they receive now, as well as in the future. However, some people who become severely affected by MS have trouble with this. This may be because speech difficulties, fatigue or memory problems have become a barrier to communication and those people cannot express their wishes. Or it may be because they have never talked about their wishes, and families, carers and health care teams are unaware of them. It may also be because wishes that they have expressed, or the views of family members, have not until now had to be taken into account legally, so decisions have been taken by health care professionals only. This situation has improved, and now each individual has the opportunity to direct what care they receive now and in the future. This is due to the new Mental Capacity Act 2005 which came into force on 1 October 2007.

The Mental Capacity Act 2005

The Mental Capacity Act makes new law about the way in which decisions are made by, and on behalf, of people with impaired mental capacity and aims to support people with impaired capacity so that they are given every opportunity to make decisions for themselves. Everybody has the right to make choices about the care they receive now and in the future. It is a basic principle of the law on consent that a mentally competent adult can refuse treatment for a good reason, a bad reason or for no reason at all.

'It is a basic principle of law on consent that a mentally competent adult can refuse treatment for a good reason, a bad reason or for no reason at all.'

There are five key principles

- Every adult has the right to make his or her own decisions and must be assumed to have capacity to do so unless it is proved otherwise
- A person must be given all practicable help before anyone treats them as not being able to make their own decisions
- Individuals must retain the right to make what might be seen as an unwise or eccentric decision
- Anything done on behalf of a person who lacks capacity must be done in their best interests
- Anything done for or on behalf of a person who lacks capacity should be the least restrictive of their basic rights and freedoms

The act provides a legal framework to protect patients with impaired capacity and also protects the carers who make decisions about their care and treatment. The Mental Capacity Act code of practice is available from the government Ministry of Justice Website. It provides guidance and information on how the Act will work on a day to day basis for anyone who works with or cares for people who lack capacity, including family, friends and unpaid carers. You can download it from www.justice.gov.uk or order a copy on 0870 600 5522.

Lasting power of attorney (LPA)

Lasting Powers of Attorney (LPAs) allow you to choose someone you trust to look after your affairs and take decisions on your behalf if necessary. They replace Enduring Powers of Attorney (EPAs).

You can specify what decisions you wish your nominated attorney to make on your behalf. You can give them a general authority to decide things. Alternatively, you could exclude certain welfare decisions. Or, you could list only specific matters or decisions, such as refusal of life sustaining treatment (like artificial feeding and hydration). It is important to note that you can only instruct the attorney to refuse life-sustaining treatment if this is clearly stated in the associated legal document that gives them the power of attorney.

LPAs now cover health care and consent to medical treatment, as well as decisions about property and financial affairs. As they can only be used after they have been registered with the Public Guardian, (see below) they will be under more scrutiny and ensure that any decisions made on behalf of people lacking capacity are in their best interests.

Anyone can be an attorney; they do not have to be a lawyer. They could be a family member or someone else you know and trust. You can have more than one. If this is the case you may want to ensure that they can easily communicate and get on with each other to avoid any difficulties.

If you decide to nominate an attorney, it can be helpful to involve them in the process from the beginning, because they will need to agree to act on your behalf and will take on a number of wider legal duties and responsibilities.

An application to appoint someone as your attorney should be made on a specific LPA form which is available from the Court of Protection, or legal stationers. It must also be registered with the Court of Protection. (see below)

In Northern Ireland the existing power of attorney regulations still apply and in Scotland, a separate 'Adults with Incapacity Act' (2000) applies, but the provisions are similar.

What if I have no one to act for me?

There is a new service called the Independent Mental Capacity Advocate service. (IMCA) which aims to help people who lack capacity to make difficult decisions. These decisions may include medical treatment choices, or where they live. It is aimed at people who do not have relatives or friends to speak for them. They will only be involved where decisions are being made about serious medical treatment or a change in the person's accommodation where it is provided by the National Health Service or a local authority.

More information is available on all aspects of the Mental Capacity Act from the Ministry of Justice. Details are at the back of this booklet.

The act has created two public bodies to support further support people who lack capacity.

The Court of Protection

A new Court of Protection has been created to help people who lack capacity and have no one to appoint as an attorney. The court of protection can appoint deputies to make decisions on their behalf if need be. The new office will be particularly important in resolving complex or disputed cases involving, for example, about whether someone lacks capacity or what is in their best interests.

The Public Guardian

This office is the registering authority for LPA's and supervision of court appointed deputies who can act for

someone who lacks capacity. They will also work together with other agencies like the Police and Social services.

The Government's Office of the Public Guardian has details of how to appoint someone as your attorney in England and Wales.

In Scotland contact the Office of the Public Guardian (Scotland)

In Northern Ireland, the Citizens Advice bureau can provide further information.

All contact details are in the back of this booklet.

Advance directives, decisions, statements and living wills

The two terms 'advance directive' and 'advance statements' are often used interchangeably but they are different.

To make things even more confusing an 'advance directive' is also sometimes referred to as an 'advance decision' or 'living will'. Below is an explanation of what these terms actually mean and how they work.

Advance directives

An 'advance directive' also called an 'advance decision' or 'living will' allows you to **refuse** a specific medical treatment some time in the future, should you lose the capacity or ability to communicate your wishes regarding that treatment. If you intend this to apply to the refusal of a possible life sustaining treatment then the directive must be in writing, signed and witnessed. This may apply to you if you wish to refuse cardiopulmonary resuscitation (CPR), ventilatory support (life support machine) in the event of breathing difficulties or the insertion of an artificial feeding tube (called 'percutaneous endoscopic gastrostomy' or PEG tube for short) that gives you the sustenance you need if you can no longer eat or swallow safely.

An advance directive is legally binding if it meets the following conditions:

- You are over 18
- It is clear
- It was made when you were mentally competent and you had been fully informed about the consequences of refusing treatment, including the fact that it may hasten death
- You intended the refusal to apply in the situation that has arisen
- The decision was made by you, on your own and not under the influence of others

'It is a basic principle of law on consent that a mentally competent adult can refuse treatment for a good reason, a bad reason or for no reason at all.'

There are no fixed legal requirements regarding the format of advance directives, but the British Medical Association suggests that the following should always be included:

- Full name
- Address
- Name and address of GP
- Details of whether advice was sought from health care professionals when drawing up the directive
- Signature
- Date drafted and reviewed
- Witness signature
- A clear statement of your wishes, either general or specific
- The name, address and telephone number of any person nominated as an attorney, if there is one
- If relevant, the date of any revisions or changes to the directive, including appropriate signatures to validate the changes

An advance directive does not have to be drawn up by a lawyer to make it legal, although where there is uncertainty a lawyer may be able to help ensure that views are clearly expressed. Consultation with a doctor is not essential but may be useful to explore treatment options and demonstrate that an informed decision-making process has occurred. However, it is generally advised that it is in written format, as casual remarks about health care can not be used as the basis of an advance directive.⁵ The directive also needs to be regularly reviewed and should be updated as and when a person's wishes change. It only comes into force when a person with severe MS is unable to make or communicate a decision.

Advance statement

Advance statements are general statements of your views or wishes. You can make an advance statement to **request** certain forms of medical intervention and make positive statements about the range of treatments and types of care you wish to receive in the event that you lose capacity to express your views in the future. For example, if you are concerned that you may not be resuscitated in certain situations where breathing or circulation has stopped, you may want explicitly to state that you wish to be resuscitated. Alternatively, you may wish to specify your feelings about

the type of residential care you may be placed in. These statements are not legally binding. However, health and social care professionals are obliged to consider them.

Assisted dying

Advance directives often become confused with the euthanasia and assisted suicide debate. This is in part because the Voluntary Euthanasia Society (now known as 'Dignity in Dying') was one of the first organisations to develop a set format for writing advance directives.

Advance directives actually allow you to take some control over end-of-life decisions, which may involve life-prolonging treatment. Advance directives do not permit illegal actions and are not concerned with taking measures to end a person's life. At present, euthanasia and assisted suicide are illegal under British law.

What particular decisions may require advance directives or statements?

'There are a number of medical treatments or therapies which you may want to consider when making an advance directive or statement.'

There are a number of medical treatments or therapies which you may want to consider when making an advance directive or statement:

Artificial feeding

People severely affected by MS can develop a degree of difficulty in swallowing which may lead to excessive saliva, weight loss, a lack of interest in food, a fear of choking, and malnutrition.

Regular assessments of how much is being eaten and swallowing should be completed by a team including speech and language therapists, dietitians and occupational therapists, so that nutrition by mouth can be maintained for as long as possible. However, it may become necessary to consider using a feeding tube. Before deciding on a feeding tube, a number of factors will be considered, including a person's ability to undergo the procedure of placing the feeding tube, if there is suitable community and carer support, and any cultural or other beliefs about diet. Family may want to be considered in this decision too.

When making decisions about artificial feeding it is important that the benefits of starting feeding by tube, such as improved skin condition (which is very important for managing pressure sores), weight gain, and being more mentally alert, outweigh the likelihood of any complications. The fact that the procedure may prolong life also needs to be considered. This may be seen as a benefit or a downside, and is the decision of the person with MS. Individuals may also wish

to think about this in advance. Severe swallowing problems can be associated with speech problems and if this decision needs to be made in practice, a person may find they are experiencing communication difficulties.

Artificial ventilation

At some point there may be a need to discuss issues around ventilation. If someone severely affected by MS also has swallowing difficulties there may be a risk of aspiration (food or liquid going down the wrong way into the lungs). This is often highlighted by an increase in frequency and severity of chest infections such as pneumonia. When looking at this problem it is important that the risks of chest infection and possible treatment options are explained. It may be appropriate to consider a tiered or stepped approach to treatment, considering at what point someone may wish to stop active treatment, if at all, and at what level with each infection. For example, someone with severe MS might want only oral antibiotics and/or physiotherapy. Alternatively, they may want intravenous antibiotics and/or physiotherapy proceeding to tracheostomy (an operation in which an opening is made in a person's throat to open the airway and a tube is inserted to enable breathing) and artificial ventilation (sometimes referred to as 'life support'). Again, it is often helpful to consider these factors in advance when communication is not an issue.

Cardiopulmonary resuscitation – CPR

Guidance from the British Medical Association, Royal College of Nursing and the Resuscitation Council emphasises that each person admitted to hospital must be assessed for their wishes on resuscitation (if the heart stops or breathing ceases).⁶ There can be no blanket policies and no discrimination on the grounds of age or perceived quality of life.

The Patient's Rights Charter clearly states that a person has a right to be resuscitated if the procedure is reasonably likely to be successful and if there is a reasonably good prognosis following resuscitation.⁷ This right is reinforced under Article 2 of the Human Rights Act (1998), which says that everyone's right to life shall be protected by law, and that no-one shall be deprived of life intentionally. There is also a duty of care owed by medical and nursing staff to their patients. Because of this, 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 also likely to be at a time of heightened stress and vulnerability as they are being admitted at a time when their MS has got worse, for example with an acute infection. In addition, this discussion will be undertaken by unknown hospital staff, often under pressure of time. It is preferable to have considered this decision prior to hospital admission with family, and with carers, key workers, health and social care professionals that are familiar. This way, decisions can be carefully considered, and friends and family can be consulted.

Example of a 63-year-old woman with very advanced secondary progressive MS

- She could only use aids and assistive technology controlled by her mouth
- Repeated risk of aspiration
- Developed chest infection
- Admitted to hospital
- Deteriorated further
- Required ventilation to live

This woman was fatigued and breathless when she was admitted to hospital. She was unable to communicate her wishes effectively. Health care professionals felt that ongoing ventilation was not in her best interests and not what she would have wanted. They asked for a palliative care assessment. However, when the palliative care consultant had a full and frank discussion with the woman's husband it was clear she had expressed her firm desire that she wanted all life-prolonging measures. She considered herself to have good quality of life and wished to 'be around to boss her husband for a little longer'. She continued to be ventilated and made a good recovery. She was referred to the community palliative care team on discharge and was visited regularly at home. She continued to suffer recurrent chest infections and on her third acute admission decided on a more conservative treatment of oral antibiotic treatment only. On her next admission she took up the offer to move to the hospice (see page 20 for a definition of hospice) where time was taken to discuss end-of-life issues. During a subsequent chest infection she died peacefully at the hospice whilst using antibiotics for symptom management.

Practical help and support

Everyone affected by severe MS, family, friends, carers, needs practical help and support. This can greatly improve the quality of life for all. Services are generally designed to be flexible so they may be tailored to each individual's needs, and government policy is encouraging this more and more.

Below is a summary of what practical help is available. Systems can vary from region to region and you may need to contact local organisations to determine exactly what is on offer in your area.

Care when living at home

MS affects each person differently. But, living with severe MS is very complex for everyone involved, including carers and family.¹ It is therefore essential that everyone has the support they need, and a complete care package is provided by the various services available. Such a care package should address physical symptoms, psychological difficulties, as well as delivering financial and practical help. This kind of full care package can help ensure symptoms are well managed, complications are prevented and quality of life is maximised. However, many people find navigating the systems bewildering, complex and confusing. Below is an outline of each service available and guidance on where to get further information.

Health care services

In 2003, the National Institute for Health and Clinical Excellence produced guidelines on how MS should be managed by the NHS.⁸ This guideline clearly states that people with MS should have access to specialist neurological rehabilitation services, which should include professionals from a variety of disciplines such as:

- Neurologist
- MS nurse
- Neuro-rehabilitation specialists
- Physiotherapist
- Psychologist and counsellors
- Occupational therapist
- Speech and language therapist
- Ophthalmologist
- Dietitian/nutritionist
- Specialist nurses
(for example, continence, pain, pressure care or spasticity)

Increasingly palliative care services are also being recognised as useful for people severely affected by MS. In reality, not everyone finds they can access all these specialists, however that should not prevent you from pushing for access to what is available in your area. To access these services you need to ask for a referral from your GP or another specialist you are seeing, such as an MS nurse or neurologist. These services may then be offered in an outpatient setting, unless the situation is such that it requires admission to hospital and treatment as an in-patient.

Community based services provide support in your home and can also be a great help to people severely affected by MS. These may include district nurses, health visitors and community matrons. GPs can also provide regular health checks.

'If you have any problems in accessing services, the local Independent Advice and Support Service may be able to help.'

If you have any problems in accessing health services, the local Patient Advice and Liaison Services (often known as 'PALS' for short) may be able to help. They are there to answer any questions, problems or concerns from any patient or those caring for them. The PALS telephone number is normally available from a doctor's surgery or hospital – just call the switchboard.

If there is any reason you are not happy with a health care service, and have been unable to address the problem using the PALS, you may wish to put in a complaint. Be aware that making a complaint can be distressing and time consuming. It may help to talk this through with a friend and have someone to support you with the process.

Social care

Severe MS affects the daily life of both carer and the person with MS. Anyone in this situation (carer and person with MS) is eligible for social services – this is not a favour, rather it is an entitlement. Social care is a particularly important source of practical help. It can provide aids and adaptations to the home, personal care services to help with daily tasks and needs, day care and respite care or residential care.

The first step to accessing these services is to call your local social services department and ask for an assessment. The contact details should be listed in the local telephone directory or your doctor's surgery should be able to provide you with them. The assessment may seem daunting at first, but be assured it is an information gathering exercise only. For more information about preparing for this assessment,

which is very important to ensure you get most appropriate level of services, read the MS Society publication *Getting the best from Social Services*.

If, following the assessment, Social Services decide you meet the local authority's criteria for support you will be given a 'care plan' that outlines what is on offer. If you are informed you do not meet the criteria and the reasons why are not clear, you can ask for further explanation. You can also ask for a copy of the criteria and use this to assess whether you feel the decision was fair. If you still feel the decision was unfair you can ask Social Services to review it and argue why you think you meet the criteria. Alternatively, you can also argue that the assessment was in some way incomplete, if you feel this was a problem.

The boundaries between what comes under health care and what comes under social care services can be confusing. If care needs become complex, social services may ask the local health authority to contribute to costs. In such cases a 'continuing care assessment' is needed and will be reviewed by a health panel. If successful, part of the care costs will be paid for by the health services. This process can be stressful and the criteria concerning what respective organisations are responsible for are often complex. It is therefore very important to keep good records of both your dealings with social and health care services and keep each team informed of your situation. You may also need to ask for a written explanation of how the criteria apply to your case.

Financial support

MS can significantly increase personal expenses and it is worth checking what financial help is available for both people with MS and carers. Benefits change frequently and even if you think you are getting everything you are entitled to it is worth regularly doing a benefits review to check this is the case. There are various organisations that can help you with this. For more information see the MS Society publication *Benefits and MS* and *Claiming Disability Living Allowance*.

The MS Society also offers financial assistance to people with MS. To find out more about how the MS Society can help you cope with the costs of MS, call the MS Society grants team on 020 8438 0700.

‘A palliative care team includes doctors, nurses and social workers who have undertaken specialist training that specifically helps them support people with advanced or terminal conditions.’

Palliative care

Palliative care takes a ‘holistic’ approach – in other words it considers the whole person. Pain relief, symptom management, and the provision of appropriate psychological, social and spiritual support are all vital parts of the service. Its goal is to achieve the best quality of life for people affected by incurable conditions, and their families throughout the advanced stages of their condition, and during the last stages of their lives. It can be provided in hospitals, in the community – and often in your own home. It also offers support to families after bereavement.⁹ Care can also be provided in hospices. These are not always for terminally ill patients. The average stay in a hospice is 12 to 14 days after which many patients return home.

A palliative care team includes doctors, nurses, physiotherapists, occupational therapists, chaplains and social workers who have undertaken specialist training in palliative care. They have expertise and understanding of the physical, practical and emotional impact that living with an advanced illness can bring. The doctors and nurses are skilled in managing and monitoring the physical symptoms that a person might experience. And, the social workers have particular skills in managing the difficulties that a person with severe MS and their families and friends might experience. They will also have specialist knowledge of relevant financial and other benefits that might be helpful. Some GPs offer palliative care as part of their service too.

All members of the specialist palliative care team have expertise in discussing these difficult issues sensitively and in a person’s own time, listening to what it is that each individual is finding particularly problematic.

Palliative care is based on a number of principles

- It affirms life and sees dying as a normal process
- It provides relief from pain and other distressing symptoms
- It integrates the psychological and spiritual aspects of a person’s care
- It offers a support system to help people live as actively as possible

Does palliative care help people with severe MS?

Palliative care can be particularly effective as it takes a coordinated approach to improving symptom management and quality of life. This has been seen for many years in cancer care,¹⁰ and it is now widely accepted that similar approaches are effective in the long-term management of neurological conditions.¹¹ Specialised palliative care promotes physical, psychological and spiritual well-being and emphasises quality of life and good symptom control.^{12, 13} There is also research to show that palliative care techniques help to control common symptoms of severe MS such as pain,¹⁴ spasticity,¹⁵ and breathlessness.¹⁶

Despite the clear benefits good palliative care services can offer, research completed in the late 1990s showed that the health and social care needs of people severely affected by MS were rarely met in the last year of their lives.¹⁷ More recent research also suggests that a 'silent minority' of people with severe MS fall out of acute care follow up in their final years.¹⁸ However, this is now starting to be addressed and palliative care services are provided by both health services and the hospice movement in some areas of the UK.

Is palliative care available to people severely affected by MS?

The National Service Framework for Long-term Conditions clearly states that people in the advanced stages of long-term neurological conditions such as MS should receive a comprehensive range of palliative care services when they need them.¹⁹ However, this is not scheduled to be fully implemented until 2015 and currently access to specialist palliative care is inadequate and inconsistent across the country. Despite this, some specialist palliative care providers are committed to offering services to those who need them.²⁰

If you feel specialist palliative care may be of benefit to you, or someone you know, you can ask for a specialist palliative care assessment to be carried out. Your GP, hospital specialist or any member of therapy team (such as an MS nurse) can make a referral or you can refer yourself directly to your local service. They will need to discuss this referral with your doctor before they make an assessment. The assessment would normally be carried out by a community palliative care team in your area and take place in your own home. There are also specialist palliative care doctors and nurses based in hospitals, and you may request to see one

of them when you attend an outpatient appointment with your neurologist. Most community palliative care teams also work closely with a local inpatient unit. This is normally a hospice. Some hospices also offer day care, access to complementary therapies, physiotherapists as well as the possibility of inpatient care. Please see the list of useful organisations at the end of this publication for the contact details of Hospice Information which will be able to direct you to your local specialist palliative care team.

Respite and residential care

‘Respite care can be provided in the person’s own home, in a care home, hospice or other facility, or in a day centre.’

Respite care

Respite care is short-term complete care designed to give both carers and people with severe MS a break from the usual routine of caring and being cared for. Respite care can be provided in the person’s own home, in a care home, hospice or other facility, or in a day centre. Some organisations provide a range of respite care services including rehabilitation and complementary therapies. The main types of respite care are as follows:

- **Planned respite:** Pre-planned opportunities for the person with MS to stay in a residential setting, so they and their carer can enjoy different activities.
- **Emergency respite:** Provision of care at short notice, either in the home or a residential setting.
- **Respite care at home:** Providing support in the home, or in the home of a substitute carer.
- **Holiday respite:** Annual short breaks for the person with MS, sometimes with the carer.

Respite care can also be a good way of socialising and getting involved in activities that are difficult to enjoy at home. Many respite care centres offer days out, as well as chances to meet new people.

For more information call the MS Society respite care team on 020 8438 0925.

Long-term residential care

Sometimes, coping at home with the care needs of a person very severely affected by MS can become difficult. There may come a time when longer term residential care, either on a temporary or permanent basis, is needed. Decisions around this can be extremely distressing and difficult, and it can help a great deal to have appropriate information to hand.

If needs are primarily for social care (help with day to day tasks), the first step in accessing care is to contact your local authority and ask for an assessment (see social care on page 18). This can help you gain access to practical day-to-day support, respite care, temporary and sometimes more permanent residential care. Be aware that these services are means tested. In other words, if you have more than a certain amount of income or savings they will not be fully funded.

If you have a very high level of disability and complex symptoms, and primarily need nursing and medical care (rather than practical day-to-day social care), you may be entitled to funding from the NHS. The first step to find out if you are eligible, is to speak to your GP or MS nurse about a 'continuing care assessment'. This assessment needs to be completed by the local primary care trust to show you meet the local health authority's 'continuing care criteria'. If it is found that you do meet the criteria for 'continuing care', the care services may be partially or fully funded by the NHS. Full funding is quite rare and only occurs where a person has very complex health care needs.

Be aware that these criteria vary from region to region and can be very confusing – many people ask for them to be explained.

If you have an assessment and feel the outcome is unfair, ask for a copy of the criteria, also ask for an explanation of how your case fits the criteria, and if appropriate, ask for the case to be reviewed. If you are still unhappy with the outcome, you can complain.

A case study on NHS funding for care – The Grogan Case

Mrs Grogan has severe MS and was admitted to hospital in November 2002 after a number of falls. Her symptoms included bladder and bowel incontinence, no mobility and some cognitive problems. In February 2003 she was transferred to a £600 per week nursing home. Some time later she was assessed as not being entitled to fully funded NHS care. As a result, she had to sell her home to meet £100,000 costs.

However, she decided to challenge this decision and went to court. The judge agreed with her saying that the criteria used were 'flawed' and that her case should be reconsidered. The Judge also called for guidelines to be renewed by the Department of Health and it is hoped the situation will soon improve.

To find out more about the options see the MS Society publication on *Finding and Funding Residential Care*, which focuses on various concerns people may have when considering residential care, including respite and long-term care. It explores how to go about finding a suitable care home and assessing the quality of their services. Also included is guidance on meeting the costs, both in terms of planning ahead and meeting immediate needs.

End-of-life care

The sad fact is that over 60 per cent of people die in hospital, though most want to be at home in their last few weeks. The Department of Health paper Building on the Best: Choice, Responsiveness and Equity supports people's right to choose where they want to die. However, communication problems may become a barrier to people being able to express choice on this issue as they reach the end of their lives. It may therefore be helpful if discussion can take place in advance about whether hospital is the best place of care for someone or whether they would choose to remain at home or prefer another less 'acute' care setting, such as a hospice.

Symptoms that may occur in the last few days of life are common to many different illnesses including MS. They might include feeling breathless or nauseated. People may become a bit confused or have problems sleeping. They may have pain, or feel very restless, or feel an overwhelming sense of tiredness. Appropriate care teams that include palliative care specialists as well as hospice, district or MS nurses, carers and GPs can help manage these symptoms during the last few days.

Decisions about how these should be managed and in what setting will need to involve family, friends and carers too.

To learn more about options in your area, contact your GP, MS nurse or one of the organisations listed on pages 25-28. Accessing appropriate specialised care can provide comfort in the last few days of life wherever someone wishes to be: a hospital; hospice; residential care or at home.

Further information

MS Society publications

The MS Society has publications on a wide variety of topics, including information for people just diagnosed, types of MS, managing relapses, and social services. For a publications list and order form visit the website www.mssociety.org.uk or call 020 8438 0799 (Monday to Friday, 10am-3pm).

MS Society website and magazine

Keep up to date with news relating to MS with the MS Society website www.mssociety.org.uk and members' magazine, *MS Matters*. Details about *MS Matters* are on the web and in the Society's publications list.

MS Helpline

The award winning MS Helpline offers confidential emotional support and information to anyone affected by MS, including family, friends, carers, newly diagnosed or those who have lived with the condition for many years. Information about MS is available in over 150 different languages by speaking to a Helpline worker via an interpreter. Call freephone **0808 800 8000** Monday to Friday, 9am-9pm, except bank holidays, or email helpline@mssociety.org.uk.

MS Society National Centre, Information Centre

Based at the MS National Centre in London, the Information Centre is equipped for visitors to read or locate books and journals or view videos and DVDs. The Information Centre also runs an information line: 020 8438 0799, Monday to Friday, 10am-3pm, which you can call to request publications, research articles or other information about MS.

Local information centres

There are MS Society local information and support centres in many locations around the country. These centres are staffed by volunteers who can help you with information about MS and services in your area. Call 020 8438 0799 for the details of your nearest centre.

Local branches

The MS Society has a network of some 340 local branches across the UK. The branches – run by trained volunteers – provide information about MS and local services, a chance to meet others affected by MS and take part in a range of activities. For more information check the MS Society website or call 020 8438 0759.

Useful organisations

Ability net

Helping disabled people use computers and the internet.
www.abilitynet.org.uk

Age Concern

Has guidance various issues associated with ageing including writing advance decisions and statements.

Astral House
1268 London Road
London SW16 4ER
Telephone 0800 00 99 66
www.ageconcern.org.uk

Carers UK

The aims of the organisation are to encourage carers to recognise their own needs, and to provide support.

Helpline 0808 808 7777
(Wednesday to Thursday 10am-12pm and 2pm-4pm)
www.carersonline.org.uk

Crossroads

Caring for carers.
Telephone 0845 450 0450
www.crossroads.org.uk

Cruse Bereavement Care

Offers free bereavement support, advice and information.

Cruse House
126 Sheen Road
Richmond
Surrey TW9 1UR
www.crusebereavementcare.org.uk
Helpline 0844 477 9400

Dignity in Dying

For more information on Living Wills and advance directives.
Telephone 0870 777 7868
www.dignityindying.org.uk

Help the Hospices

A national charity that works to improve the quality of and access to hospices in the UK.

Hospice House
34-44 Britannia Street
London WC1X 9JG
www.helpthehospices.org.uk

Hospice Information

This joint venture between Help the Hospices and St Christopher's Hospice offers offering a comprehensive enquiry service and website.

info@hospiceinformation.info
www.hospiceinformation.info
Telephone 0870 903 3 903
Fax 020 7278 1021

ITCH network

Advice and support to get you started using computers.

Telephone 0800 269545
www.itcanhelp.org.uk

Mind

Offers guidance on mental capacity issues, writing advance decisions and statements.

15-19 Broadway
London E15 4BQ
Information line 0845 766 0163
www.mind.org.uk

Ministry of Justice

Government site with information on the Mental Capacity act 2005.

Telephone 020 7210 8500
www.justice.gov.uk

The Government's Office of the Public Guardian has details of how to appoint someone as your attorney in England and Wales.

www.publicguardian.gov.uk

In Scotland contact the Office of the Public Guardian (Scotland)

www.publicguardian-scotland.gov.uk

In Northern Ireland, the citizens advice bureau can provide further information. Find your local office at www.citizensadvice.co.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.

The Fitzpatrick Building
188-194 York Way
London N7 9AS
Telephone 020 7697 1520
www.ncpc.org.uk

The Patients Association

Has guidance on writing advance decisions
and statements.

PO Box 935
Harrow
Middlesex HA1 3YJ
Helpline 0845 6084455
www.patients-association.org.uk

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With thanks to: Dr Cynthia Benz, Dr Alasdair Coles, Jocelyn Guttery, Sally Plumb, Liz Read, Douglas Joy, Carol Stevens, Joanna Black and all those people affected by MS who contributed to this publication.

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

Suggestions for improvement in future editions are welcomed. Please send them to infoteam@mssociety.org.uk.

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Reviewed and updated by the information team,
April 2008

Multiple Sclerosis Society

Multiple sclerosis (MS) is the most common disabling neurological condition affecting young adults and we estimate that around 85,000 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 50 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

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 9080 2802

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

National MS Helpline
Freephone 0808 800 8000
(Monday to Friday, 9am-9pm)

www.mssociety.org.uk

Registered charity 207495