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MS Essentials

For people living with MS

Complementary and alternative medicine

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Most people with MS take an active interest in managing their health, and it is estimated that between 50 and 75 per cent have used complementary or alternative medicine as part of their lifestyle.^{1,2} This may be because people with MS feel that conventional medicine no longer has all the answers.³ Or, perhaps because people feel they have more control over their health and well-being when they use complementary and alternative medicines. Others may find the 'holistic' approach to treatment appeals, as it may look beyond the physical and take emotional and spiritual issues into account too. Whatever the reason behind this treatment choice, many people with MS report that complementary and alternative therapies help them to feel better.¹

Unfortunately, there is little research to show how effective or safe many of these medicines may be. Despite this, conventional healthcare professionals' attitudes to complementary and alternative medicines are changing and becoming more positive. This greater acceptance is shown by their increasing availability on the NHS. Almost half of GP practices in England now provide access to some sort of complementary and alternative medicines for NHS patients.^{4,5} If you cannot get a particular complementary or alternative medicine on the NHS, most are easy to access privately, but you need to take appropriate precautions.

It is important to do some background research, and talk over the idea with your doctor who can check that it is appropriate for a person with your medical history and that it will not react badly with any other medications you are taking. It is also important to find a properly trained and qualified practitioner – that is the person who is providing the treatment, such as an acupuncturist, chiropractor, homeopath or osteopath.

What are complementary and alternative medicines?

‘Complementary and alternative medicine’ is the name given to a broad group of health-related therapies and disciplines which are not considered to be part of mainstream medical care.² They exist largely outside the institutions in which conventional health care is taught and provided.⁴ These medicines may be used in a ‘complementary’ or ‘alternative’ manner. In other words, they may be used alongside conventional health care and accepted as ‘complementing’ it, or they may be provided as an ‘alternative’ to conventional health care. The majority of people with MS follow the complementary approach and use these therapies in combination with conventional medicine.⁶

Other terms used to describe complementary and alternative medicines include ‘holistic’ or ‘natural’ medicine. The term ‘natural’ can be misleading. Many complementary and alternative medicines are processed and are as ‘unnatural’ as any other drugs, and about 25 per cent of medicines produced by the pharmaceutical industry are derived in some way from natural products such as herbs.² The term ‘holistic’ refers to those therapies that look beyond the physical and address emotional and spiritual issues too.

There are many different types of complementary and alternative medicines. The most popular in the UK include: acupuncture; chiropractic; herbalism; homeopathy and osteopathy.⁴ An overview of the more popular ones is included on pages 10 to 19. There are also various other non-standard treatments and therapies available that are generally less well known and are not normally included in the listings of complementary and alternative medicine. These more obscure treatments are often promoted to people with specific conditions and those sometimes targeted at people with MS are described on pages 19 to 23.

Can I believe the claims?

There is a lot of information available about complementary and alternative medicines, including a range of books and many websites. The problem is finding information that is objective and accurate.⁶ It is easy to become overwhelmed and confused when trying to establish how effective a complementary or alternative medicine may be. This is a particular problem when looking on the internet, where information is easily accessible, but often of questionable quality.⁷ Anyone can publish a website, without needing to supply names, qualifications or sources, let alone whether the information is based on scientific research.

It is possible to find numerous sales pitches that include personal statements and anecdotal claims about all kinds of treatments. If you are considering using a complementary or alternative medicine, watch out for products that make big promises, say they are scientifically proven or can 'cure MS'. Buying these can be a waste of money, lead to unrealistic expectations and can cause much disappointment. In addition, some complementary or alternative medicines may be harmful, and others can have dangerous interactions with other medications.⁸ For this reason, the decision to use complementary and alternative medicines should be talked over with your doctor, who can advise you of any risks.

While many people report that a complementary or alternative medicine has helped them, others give them up as they feel it has little or no impact. One research study that questioned more than 3,000 people with MS, found that over 55 per cent of those who had tried a complementary or alternative medicine stopped because they felt it was ineffective.¹

Have clinical trials tested what works?

People often ask if there is any 'evidence' that a particular treatment works. Various clinical trials have tested the effectiveness of complementary and alternative therapies in treating MS. You can find out more about these on pages 10 to 23. However, when compared to the number of clinical trials examining the use of conventional medicine in MS, this area is still poorly researched.⁴ In addition, questions have been raised about the quality and design of the trials completed for complementary and alternative medicines in MS.⁹

One reason for the lack of quality research in this area is that complementary and alternative medicines are rarely suited to traditional research techniques due to their very nature.

A report, published by the House of Lords in 2000, looked at this problem. It stated that practitioners and researchers should try to build up scientific evidence for complementary and alternative medicine with the same rigour that is required for conventional medicine, using clinical trials where appropriate, and other research designs.¹¹ Some ideas have now been put forward about how clinical trials may be adapted to better suit complementary and alternative medicines and it is hoped this will encourage further research.¹⁰ Applications for research grants from those wishing to study the use of complementary medicines in MS are also welcomed by the MS Society.

In the meantime, the lack of clinical evidence does not necessarily mean complementary and alternative therapies do not benefit some people with MS. One US research study showed that over half of all people who had tried various complementary and alternative medicines including yoga, herbal treatment, chiropractic, massage, and nutritional supplements, thought they had been helpful.¹²

What is the view of the NHS on using complementary and alternative medicine for MS?

The National Institute for Health and Clinical Excellence (NICE) guideline on MS sets out how MS should be treated by the NHS. These recommendations are based on research evidence and it is the first time a document of this kind has mentioned complementary and alternative medicine.¹³

The guideline says that there is some evidence that reflexology, massage, t'ai chi, magnetic field therapy, neural therapy, fish oils and the combination of some forms of complementary therapy (known as 'multi-modal therapy') may be helpful for people with MS in terms of their general sense of well-being.¹⁴ However, it goes on to say there is insufficient research evidence to give firm recommendations. Complementary and alternative medicines that have not been well researched in relation to MS are not mentioned. This means that the therapies listed are not necessarily those that people with MS most frequently use or know about.

The good thing about the approach NICE took is that it brings the use of complementary and alternative medicines out into the open. You do not need to feel reluctant to talk to your doctors about complementary and alternative medicines you wish to use or are using – quite the opposite, and the NICE guideline recommends you do just that.

Availability and cost

Almost half of GP practices in England now provide access to some sorts of complementary and alternative medicines for NHS patients.^{4,5} Each local practice, primary care trust or hospital trust decides individually whether or not they will provide complementary and alternative medicines on the NHS.¹⁵ If they do provide them, they may have complementary and alternative medicine practitioners working alongside doctors, or doctors providing complementary and alternative medicine themselves. When provided on the NHS, it might be at no extra cost or you might be asked to pay something towards it. Do check before you go for any appointments.

Complementary and alternative medicines are also often provided by hospices, palliative care services, and in some hospitals and pain clinics.⁴

If you cannot get a particular complementary and alternative medicine on the NHS, most are easy to access privately either in a clinic or through practitioners who have clinical practices in their home. Charges for individual appointments and for full courses of treatment can vary significantly, so do check cost before making a commitment. People are urged to take great caution if a practitioner pushes for many sessions to be booked and paid for in advance and of 'bulk buying' products. Also if a therapy seems to have an excessive cost, it is suggested people 'err on the side of caution', and check costs with the appropriate regulatory authority.

Some private health insurance schemes and medical cash plans will cover the costs of selected complementary and alternative medicines. Alternatively, some local Healthy Living Centres and MS National Therapy Centres may be able to offer complementary and alternative medicine at subsidised prices to those who cannot afford them otherwise.

Regulation of complementary and alternative medicine practitioners

There is little regulation of many complementary and alternative medicine practitioners, and in some cases it can be easy for anyone to set themselves up as a practitioner. The exceptions to this are osteopathy and chiropractic, both of which have strong regulatory bodies that have been established by law.⁴

Limited regulation means it is important to choose a practitioner who belongs to a professional organisation or regulatory body, where possible. By checking the membership requirements of an organisation, you can establish how well qualified a practitioner may be. For example, membership may be based on any number of different things such as completing a programme of academic study, a specified number of hours of clinical training, or an interview and assessment. Knowing a practitioner has done appropriate study and training is reassuring, and if you find out they have had very little training you may not wish to use them.

In some cases there may be more than one regulatory body, and regulation systems may vary between them. In this case, you may wish to compare membership requirements.

Which do I use?

There are many different types of complementary and alternative medicines and it can be confusing when deciding what might be appropriate for you. While some people may find one type of therapy works well for them, another person may find they do not get the same benefit. You may wish to consider a number of therapies before making a final decision. Pages 10 to 23 outline some of the most popular and also includes a list of other non-standard therapies often targeted at people with MS.

Once you have decided which therapies you are interested in, ensure you research how that particular therapy is regulated. Also, if you are thinking of taking a complementary or alternative medicine because new symptoms have appeared or there is a change in your condition, you should always discuss this change in health with your doctor first. Your health care team can assess your situation and identify any dangerous or easily treatable symptoms. They can also tell you if the complementary or alternative medicine you are considering should not be used with your existing medications because of contraindications, or if it may have a negative impact on the symptoms you have.

Never change or stop taking prescribed medication without talking to your doctor first.

How do I find a practitioner?

A practitioner is the person who provides the complementary or alternative medicine. Examples include an acupuncturist, chiropractor, homeopath, masseur or osteopath.

Some people find a practitioner via their doctor, MS nurse or another member of their health care team. Others look for a practitioner independently. In either case, it is important to do your research before making a commitment. Check that they are properly trained, have qualifications and whether they are a member of a regulatory or professional organisation.

Alternatively, many regulatory organisations can provide advice and details of practitioners in your area. A list of such professional organisations is included on pages 26 to 30. The types of questions you may wish to ask the regulatory organisation include:

- How long has the organisation existed and how many members do they have?
- How do practitioners register and must they pay a fee?
- What training and/or qualifications must members have?

- Is there a complaints procedure and a system for removing a practitioner from the register if there have been complaints against them in the past?
- Can the organisation provide a list of practitioners?

Word of mouth can also be a useful way of finding a practitioner, but it is still important to check if the practitioner is trained and registered with a regulatory or professional organisation.

What should I do before making an appointment?

Once a practitioner has been identified, or if you already have a practitioner in mind, you should talk to them to establish if the complementary or alternative medicine they offer and their establishment is appropriate for you. It is recommended you check the following before you commit to an appointment:

- Are they a member of any regulatory body or professional organisation, and if they are, what does membership entail?
- How long did they train for, what qualifications do they have, and how long they have been practising?
- How does the treatment work and feel, and who benefits from it?
- Does the practitioner have experience of treating people with MS and is the method appropriate for someone who has MS?
- Are they insured so you can be compensated if anything goes wrong? For example, professional indemnity insurance. This not only means you can be compensated if something goes wrong, it also highlights good professional standards.
- What is the cost of a full course of treatment and does the first appointment cost more?
- How long is the course of treatment likely to be?
- Does the practitioner have any information about their practice and the therapy that they can send out to you in advance?
- Is there any preparation you should make before treatment? For example, not eating for a short time or wearing a particular type of clothing.
- Is a record of treatment and outcomes kept? And, can you have access to information, for example if you want a copy of records for your doctor or neurologist?
- Is the clinic or place that they practice accessible?

At the appointment

Before the treatment begins, make sure the practitioner is aware of your MS, any other medical conditions you have, and any medications you take. At the appointment, the practitioner should take a full history of your condition and explain what the process will involve. They should welcome any questions you have and keep you well informed throughout the treatment period.

The practitioner should tell you to see your doctor if they realise you might have something serious that your doctor does not know about, or if they identify any further health conditions that you or your doctor are not aware of.

They should also tell you if they cannot help, and if possible suggest you see someone else.

What should I do if I am unhappy with a complementary or alternative medicine?

There are various reasons why you may not be happy with a complementary or alternative medicine. These include: that you do not like the treatment or the way it makes you feel; that you have been hurt or injured; or that you do not like the way the practitioner is behaving towards you. Some of these problems can be relatively easy to sort out, others are not. The first thing is to try and explain to your practitioner what the problem is. If there is an issue with the treatment, it may be possible to adapt it to suit you better. Alternatively, it may be that this particular treatment is not the one for you.

As with conventional medicine, it is important for you to have a good professional relationship with your practitioner. This will help you get the best out of a treatment. However, relationships don't always work. If you find there are problems, it may be best to find a different practitioner.

If you feel you are unable to sort out the problem by talking to your practitioner, or are not satisfied with a treatment, you may wish to complain. There are different approaches depending on whether your practitioner was accessed via the NHS or privately:¹⁵

- **If the treatment was received via the NHS**, you may first wish to talk about any problems experienced with your doctor or the complementary health care service manager (if there is one). You can also use the standard NHS complaints process. Before officially complaining in England, you may wish to contact the local Patient Advice and Liaison Service (PALS) who can answer questions, problems or concerns of a non-medical kind. The PALS number is available from a doctor's surgery or hospital. PALS can also help you with the complaints procedure.

In Scotland, you need to contact the trust or health board patient liaison or complaints officer. In Wales, the trust or local health board complaints manager, is responsible.

In Northern Ireland, the local health and social services board is responsible for complaints within the NHS.

- **If you are seeing your practitioner as a private client,** the first thing is to contact any regulatory authority or professional association of which they are a member. Ask if they have a complaints procedure and use this if appropriate. There may also be a complaints procedure associated with a practitioner's clinic. Many practitioners will also be insured, so if you have been hurt or injured you may be able to get compensation this way. However, many types of complementary and alternative medicines are not regulated by law, and not all professional associations have complaints procedures or will help you with a complaint. This is why it is suggested you ask all those questions on pages 6 and 7 before you make an appointment.

If you are not happy with your practitioner's behaviour towards you and want to do something about it, you can contact WITNESS – Against Abuse by Health and Care Workers. There is also a charity called Action against Medical Accidents which aims to help people who have been harmed during a health care treatment.

Be aware that making a complaint can be distressing and time consuming. You may wish to talk this through with a friend and have someone to support you with the process.¹⁵

False claims and advertising

If you think the complementary and alternative medicine hasn't lived up to claims made about it or you have been misled, you may wish to contact the Advertising Standards Authority and register a complaint. The ASA oversee advertising wherever it appears, be it in a newspaper, magazine, TV, direct mail or web adverts (such as banners, pop-ups and emails sale promotions). The ASA can tell you what can and can not be said about a particular product. Unqualified claims about 'cures' are generally considered unacceptable and the ASA can help to get advertisements withdrawn.

If you have already paid for a treatment and want reimbursement as you feel you have been misled, you may wish to contact the Office of Fair Trading or Trading Standards.

Types of complementary and alternative medicine

This is not a list of complementary and alternative medicines recommended by the MS Society, nor is this a comprehensive list of all complementary and alternative medicines available. Rather this is a summary of all those that are most commonly asked about by people with MS and those that have been researched in treating MS. Details of all organisations mentioned are included on pages 26 to 30.

Remember to inform your doctor of any complementary or alternative medicine you are considering, so they can ensure it is safe.

Acupuncture and acupressure

Acupuncture is a component of traditional Chinese medicine. In traditional Chinese medicine, it is believed that energy, (known as 'qi'), travels through the body in specific pathways (known as 'meridians'), and that illness occurs when there is a disturbance of energy. With acupuncture, improvement of energy flow is thought to occur with the insertion of thin, metallic needles in specific points on the meridians. For acupressure, hand or finger pressure is applied to the acupuncture points. Only small or preliminary studies of acupuncture in MS have been completed.^{16, 17}

In other conditions, acupuncture appears to alleviate pain, nausea, and vomiting.¹⁸ Acupuncture is generally a well tolerated procedure, especially when it is performed by a well-trained acupuncturist. To avoid infections, sterile needles should be used.

There are about 7,500 acupuncturists practising in the UK, and one in three doctors' surgeries are making acupuncture available.¹⁵ There are two distinct styles of acupuncture – traditional Chinese and western medical. They have separate professional organisations that can provide further information and advise, including: Acupuncture Association of Chartered Physiotherapists (all members are also qualified in physiotherapy); British Acupuncture Council; British Academy of Western Medical Acupuncture; and British Medical Acupuncture Society.

Alexander Technique

The Alexander technique was developed around 1900 by Frederick M. Alexander, an Australian actor who had recurrent episodes of hoarseness while performing. To address this problem, he experimented on himself by observing various head and neck positions in a mirror. He eventually found positions of the head, neck, and spine

appeared to correct the problem by improving posture and making tasks easier. He then taught this method, the 'Alexander technique', to others. There are no formal studies of the Alexander technique in people with MS. Limited studies in other conditions suggest that the Alexander technique may improve balance, performance ability, low back pain, depression, level of disability, and breathing function.^{19, 20} There are no known adverse effects from the therapy itself, but it should not be used in a way that delays conventional medical diagnosis or treatment of serious conditions.

Alexander Technique teachers are not required to belong to any professional organisation or to have completed any specific training. However, the Society of Teachers of the Alexander Technique can provide details of its members, all of whom have completed a training course and agree to a professional code of conduct.

Aromatherapy

Aromatherapy is a healing method that uses essential oils from plants. It was practiced in some form in ancient China and ancient Greece. The form of aromatherapy that is currently used was originally developed in the early twentieth-century by a French chemist. In aromatherapy, the oils may be applied to the skin, mixed with bath water, or inhaled.

The effects of aromatherapy on people with MS have not undergone careful research. A small preliminary study of two people with MS found that treatment with aromatherapy and massage was associated with improvement in mobility, dressing ability, and personal hygiene.²¹ Other small clinical studies suggest that aromatherapy may improve anxiety, depression, pain, and insomnia, but these studies are of variable quality and some of the results have been inconsistent.^{21, 22}

It is also worth noting that although aromatherapy is usually well tolerated, oils may sometimes cause rashes or allergic reactions. Oils should not be taken internally.

There are currently over a dozen professional organisations for aromatherapists in the UK, and an aromatherapist is not required to belong to any of them or have completed any specific training. However, many of these organisations are working together as the Aromatherapy Council, with the aim of establishing professional standards and a single register of qualified practitioners. In the meantime, the Council can provide some advice and have details of some practitioners.

Chiropractic

Chiropractic medicine is based on the idea that the nervous system is important for health and that many diseases are due to poor alignments of the bones of the spine. These poor alignments are thought to cause abnormal pressure on the nerves that leave the spine. Spinal manipulation methods (known as 'adjustments') are believed to normalise bone position and relieve pressure on the nerves.

Research of chiropractic therapy in MS is limited. The clinical studies are of poor quality, and otherwise there are only reports of individual responses to this therapy.²³ In general, however, chiropractic therapy may decrease low back pain.²⁴ Although chiropractic manipulation is usually well tolerated, in rare occasions low back manipulation may cause spine trauma and neck manipulation may cause strokes.

Chiropractic is regulated by law in the UK. All chiropractors must be fully qualified to practise and must register with the General Chiropractic Council who can provide list of practitioners in your area.

Healing

Healing covers a wide range of approaches, including therapeutic touch, faith healing, and prayer. There are no research studies of these approaches in people with MS. In other groups of people, involvement in religion and spirituality has been *associated* with better health outcomes. Whether spiritual and religious involvement actually cause improved health is not known.^{20, 25} Healing methods are generally well tolerated. They should not be a substitute for conventional medicine and should not delay seeking advice from a doctor.

Healing is not regulated by law. Practitioners are not required to have completed any specific training or be a member of any professional organisation. There are, however, numerous healing organisations in the UK, which all work separately. It is suggested that the questions on pages 6 and 7 are asked before making an appointment.

Herbal medicine

Herbs contain hundreds of chemical constituents. Some of these chemicals can be therapeutic and others can be harmful. The use of herbs in medicine has a long tradition in many cultures. In traditional Chinese medicine, herbal therapies were initially developed around 3,000 BC. And, many modern drugs are actually related to chemicals in herbs. Today, it is estimated that 25 per cent of prescription

medications and 60 per cent of over-the-counter drugs are derived in some way from herbs.

Among the various Western herbal products, some may be useful as therapies for MS. Examples include, cranberry for prevention of urinary tract infection, St John's wort for depression, valerian for insomnia, and psyllium for constipation. Some studies report beneficial effects with some forms of herbal medicine. However, these studies are difficult to interpret and are of variable quality.^{16, 26} Some herbs may also provoke MS symptoms or interact with medications commonly used in MS. In addition, some herbs, such as echinacea and an Ayurvedic herb, ashwagandha, appear to activate the immune system and could pose a theoretical risk for people with MS.

Herbal medicine is not regulated by law. Practitioners are not required to have any specific training or belong to any professional organisation. Currently there are a number of different professional organisations for practitioners from various herbal disciplines including Ayurveda, Chinese, Tibetan and Western herbal medicine. The European Herbal Practitioners Association works with most of them and can provide information about different disciplines.

Homeopathy

Homeopathy is one of the more popular forms of complementary and alternative medicine. Its basic principles are contrary to those of conventional medicine and basic science. Specifically, according to the homeopathic principle of 'like cures like,' if a large amount of a substance causes a particular symptom then miniscule amounts of that substance will relieve that same symptom. Homeopathy is controversial. As with many other forms of alternative medicine, there is concern that responses to homeopathic preparations are 'placebo responses' (in other words, because people believe taking a homeopathic treatment is going to have a positive effect, they feel better after homeopathic treatment even if there is no science to back this up). Research studies have not clarified this issue.²⁰ Furthermore, there are no rigorous studies of homeopathy in MS.^{16, 27} However, due to the extremely dilute preparations used in homeopathy, this approach is generally thought to carry little risk. It is claimed that some conventional medications may antagonise the effects of homeopathic remedies. However, homeopathy should not be used in a way that delays the conventional medical diagnosis or prevents use of treatments that are proven to be effective.

Homeopathy is not regulated by law and there is no single professional organisation or qualification for homeopaths in the UK. Conventional health care professionals, such as doctors, nurses, dentists and pharmacists, who have trained in and practice homeopathy can join the Faculty of Homeopathy. Details of local Faculty members who can provide you with treatment are available from the British Homeopathic Association. Other homeopaths not qualified in conventional medicine can join the Society of Homeopaths if they meet set training requirements and agree to a professional code of conduct. However, they will not be able to give conventional medical advice.

There are also five NHS homeopathic hospitals in the UK offering outpatient services to people referred by their doctor. They are considered one of the cheaper and safer ways of getting this kind of treatment and are based in Bristol, Glasgow, Liverpool, London and Tunbridge Wells.

When provided on the NHS, you will be asked to pay a prescription charge for any homeopathic remedies. NHS homeopaths are also subject to standard NHS regulation, so should you have any problems, you can follow the standard complaints process.

Massage

Massage is a healing method that has been practiced for thousands of years. It was used in ancient Egypt and China. The more popular forms of massage that are currently used are derived from Swedish massage, which was developed by Swedish doctors in the nineteenth century.

Massage may be practiced on its own or as one component of more broad-based healing methods, such as aromatherapy. One small study of massage in people with MS found that it was associated with increased self-esteem, improved social functioning, reduced anxiety and depression, and improved image of one's body.²⁸ Another small study found that a slow 'stroking' massage (that uses the flat of the hand) over the spine was associated with improvement in anxiety and muscle stiffness.²⁹

Massage is usually well tolerated but should be used with caution in women who are pregnant and in people with recent injuries, ulcers, enlargement of the liver or spleen, fever, infection, clotted blood vessels, jaundice, cancer, heart disease, and arthritis.

Massage is not regulated by law and practitioners are not required to have any specific training or be a member of any professional organisation. However, there are various organisations massage practitioners may join. Many are

working together as the General Council for Massage Therapy to develop professional standards, though these have yet to be finalised.

Multi-modal therapy

Multi-modal therapy refers to a treatment programme that includes visualisation techniques, meditation, guided imagery, expressive therapy (such as art and music therapy), concentration and memory exercises, stress management, behaviour modification, and other self-regulation techniques. People with MS who received this specific treatment programme during a research study showed improvement in various areas, including verbal learning, abstract thinking, depression, strength, and sensation.³⁰ Due to the multiple components of this therapy, it is difficult to determine which therapy may have produced the beneficial effects. Some of the specific components of multi-modal therapy have been studied in MS, and more information is given in relevant sections of this publication.

Osteopathy

Osteopathy was founded in the United States in 1874 by Dr Andrew Still. It works with the body's musculoskeletal system, which is made up of the bones, joints, muscles and ligaments. Osteopaths use their hands to diagnose and treat any problems found. Techniques include manipulating muscles, sometimes using short sharp movements, gentle massage and rhythmic joint movements. Studies indicate that these techniques decrease low back pain.²⁰ One small, short-term study found that a combination of osteopathic manipulation and a specific exercise program led to improved strength and walking ability in people with MS.³¹ Further studies of specific osteopathic methods in MS are needed to better understand how this therapy may help.

Osteopathic manipulation is generally well tolerated, but, like chiropractic manipulation, there is a low risk of spinal trauma with low back manipulation and stroke with neck manipulation.

Osteopathy is regulated by law in the UK. All osteopaths must be fully qualified to practise and must register with the General Osteopathic Council. The Council can also provide details of osteopaths in your area.

Pilates

Pilates is a form of bodywork that was created during World War I by Dr Joseph Pilates, a German inventor, boxer, and dancer. The technique was originally developed to help soldiers recover from war injuries. With the Pilates method,

individuals focus on the use and control of specific muscles during body movements. There is also an emphasis on breathing. There are no formal research studies of Pilates in MS. One small study of elite gymnasts found improved strength, jump height, and reaction times after a program that included Pilates, leap training, and pool training.³² Another small study found improved flexibility after Pilates training.³³ It is generally assumed that the Pilates method is well tolerated.

Pilates teachers are not regulated in the UK and are not legally required to have any specific qualifications. It is suggested that, before going to a class, the questions on page 7 are asked.

Reflexology

In reflexology, pressure is applied to specific areas, or zones, of the foot. These zones are believed to correspond to different areas of the body. The application of pressure is thought to improve health by increasing energy flow in the body. This concept of an underlying life force is similar to that of some other alternative healing systems such as acupuncture. One MS research study, which was not well designed, found improvement in multiple MS symptoms with reflexology,³⁴ while a better designed and larger study found that there was improvement in muscle stiffness, bladder and sensory symptoms.³⁵ Reflexology is a low risk therapy and there are no known serious side effects. It should be used with caution in those with foot conditions, including gout, ulcers, vascular disease and arthritis.

Reflexology is not regulated by law and practitioners are not required to have any specific training or be a member of any professional organisation. However, there are various organisations reflexologists may join. Many are working together as the Reflexology Forum to develop professional standards, though these have yet to be finalised. In the meantime, they can give you details of member organisations.

Reiki

Reiki is a form of energy medicine that was developed in Japan in the mid 1800s. Reiki practitioners are given 'attunements' that are meant to improve their ability to draw upon and channel healing energy.³⁶ It is believed that Reiki practitioners can direct and infuse healing energy into the body. This process is thought to rebalance energy and activate the body's own healing processes. There are no formal studies of the effects of Reiki on people with MS.

However, Reiki is generally well tolerated, though it is claimed that it should be used with caution in those with diabetes and pacemakers.

Reiki is not regulated by law and practitioners are not required to have any specific qualifications. It is suggested that, before making an appointment, the questions on page 7 are asked.

Relaxation and meditation

Relaxation is a component of several different forms of complementary and alternative medicine, including meditation, guided imagery, hypnosis, biofeedback, and progressive muscle relaxation. People with MS often report that they feel stress and anxiety. There have been studies of MS and various relaxation methods. One small study reported reduced anxiety and improved physical symptoms with meditation and imagery; another small study found decreased anxiety and a more positive outlook with imagery and relaxation techniques.¹⁶

Relaxation methods are generally low risk, though they should be used with caution by those with serious psychiatric disease, such as severe depression and schizophrenia. Relaxation may produce fear of losing control, anxiety, and disturbing thoughts. Relaxation methods should not be used as a substitute for conventional medicines for MS and related symptoms.

Relaxation and meditation practitioners are not regulated in the UK and are not legally required to have any specific qualifications. It is suggested that, before making an appointment, the questions on page 7 are asked.

T'ai chi

T'ai chi, a traditional Chinese martial art that has been practiced in China for centuries, is characterised by sequences of body postures that are connected by slow, graceful movements. T'ai chi is believed to balance opposing life forces and create emotional balance. The movements in t'ai chi may be modified for those with disabilities. One study of 19 people with MS found improved walking speed, muscle stiffness, vitality, social and emotional functioning, and ability to carry out physical and emotional roles.³⁷ A study of 'mindfulness of movement,' a component of t'ai chi, in 16 people with MS found improvement in multiple MS symptoms.³⁸ More rigorous studies of t'ai chi in MS are needed to gain a better understanding of how it may help.

T'ai chi is usually well tolerated, though it may strain joints and muscles and temporarily worsen MS fatigue. T'ai chi should be used with caution or avoided by those with acute low back pain, osteoporosis, significant joint injuries and bone fractures.

T'ai chi teachers are not regulated in the UK and are not legally required to have any specific qualifications. It is suggested that, before making an appointment, the questions on page 7 are asked.

Shiatsu

Shiatsu is an ancient Japanese form of massage. In Shiatsu, gentle pressure is applied to the meridians which, according to traditional Chinese medicine, are the pathways for energy flow in the body (see section on acupuncture and acupressure). In this respect, Shiatsu is similar to acupuncture. However, the major focus of Shiatsu is prevention.

There have not been any formal research studies of Shiatsu in MS. Generally Shiatsu is a low risk therapy, though there are rare reports of serious injury to the arteries in the neck with Shiatsu of the neck area.

Shiatsu is not regulated by law and practitioners are not required to have any specific qualifications. There are, however, many different Shiatsu organisations practitioners may belong to. These various organisations are working together as the Shiatsu General Council to develop professional standards and a single register of qualified practitioners.

Yoga

Yoga is a mind-body therapy that was developed in India thousands of years ago. Yoga is meant to unite the mind, body, and spirit. Major components of hatha yoga, one of the more popular forms of yoga, are breathing, meditation, and posture. Yoga postures may be modified for those with disabilities. Despite its popularity, there are relatively few studies of the effects of yoga on MS and other health problems.¹⁶ One well-designed clinical trial in MS found that both yoga and conventional exercise improved fatigue.³⁹

Yoga is a low risk therapy. However, vigorous exercise or difficult postures should be done with caution by pregnant women and those with heat sensitivity, fatigue, decreased balance, and significant heart, lung, or bone conditions.

Yoga is not regulated by law and practitioners are not required to have any specific qualifications. There are,

however, over ten different Yoga organisations practitioners may belong to. These various organisations are working together as the British Council for Yoga Therapy to develop professional standards and a single register of qualified practitioners. The Council can provide details of member organisations and information about yoga.

Other types of non-standard therapies

None of the therapies below are regulated by law and practitioners are not required to have any specific qualifications. It is therefore suggested you ask the questions on page 7 before making an appointment for any of these non-standard therapies.

Cannabis and cannabis extracts

People have claimed that cannabis, also known as 'marijuana', is an effective treatment for MS. Cannabis contains chemicals known as 'cannabinoids' including tetrahydrocannabinol (known as 'THC' for short). These cannabinoids have a variety of biological effects, and it is thought they may improve MS symptoms or affect how MS progresses. People who took part in a clinical trial suggested that cannabis, or cannabinoid preparations, may alleviate some symptoms, including spasticity and pain.^{2,40} Further studies of the effects of cannabis are planned in the UK.

Meanwhile, a cannabis based drug called 'Sativex' is also now available in Canada, but does not have a license in the UK. It can be prescribed by GPs on a 'named patient' basis, but this is the exception rather than the norm.

This creates a dilemma. Medically tested cannabis based treatments, of known quality, are not available to most people in the UK. Some people therefore seek to find cannabis from other sources. However, currently cannabis is a class C controlled drug. Possession, production and supply of cannabis is illegal, and what is supplied illegally can vary wildly in nature and strength. The maximum penalty for possession of cannabis is two years imprisonment. The Home Office advise that it is unlikely that adults caught in possession of cannabis will be arrested. Most offences of possession result in warning and confiscation of the drug. However, arrest, caution and prosecution may occur if someone repeatedly offends, smokes cannabis in a public place, or possesses cannabis in the vicinity of premises used by children.

Be aware that cannabis has many side effects including dizziness, sleepiness, feelings of intoxication, nausea, increased risk of seizures, poor pregnancy outcomes,

and impaired driving. High doses of cannabis may decrease reaction time, impair heart function, and produce coordination and visual difficulties. Chronic use of cannabis may impair lung function, cause heart attacks, increase the risk of lung, mouth and throat cancer, and has been linked to psychological problems.

Cooling

Cooling is a complementary therapy that is unique to MS. In people with MS, it is known that small increases in body temperature can make MS symptoms feel worse. This observation has led to the development of various cooling methods. There are simple cooling methods, such as staying in air-conditioned areas and drinking cold liquids. More complex cooling techniques utilise specially designed cooling suits. There have been many studies about cooling in MS. Fatigue is frequently reported to improve with cooling.² In the most rigorous study to date, cooling was associated with mild improvement in walking, vision, fatigue, strength, and cognition.⁴¹ Cooling is generally well tolerated, though garments may be cumbersome. There may also be discomfort with the onset of cooling. In the minority of people with MS who are sensitive to cold temperatures, cooling can make MS symptoms feel worse.

Honey bee venom

Bee venom therapy is a type of *apitherapy*, which refers to the use of bees or bee products to treat medical conditions. In bee venom therapy, bees are placed on specific areas of the body with tweezers. Typically, treatment sessions involve 20 to 40 stings and are done three times weekly. The early results of a study that looked at the impact of bee venom therapy in an animal model of MS, found it was ineffective or produced worse results than seen in the placebo-treated animals.⁴² A well-designed clinical trial of bee venom therapy in people with MS found that it did not produce significant beneficial effects.⁴³

Bee venom therapy is generally a low risk procedure, though mild side effects include itching, hives, fatigue, anxiety, and swelling and redness at the sting site. Very rarely, bee stings may cause a severe and potentially fatal allergic reaction.

Hyperbaric oxygen therapy

Hyperbaric oxygen therapy is a form of treatment in which oxygen is administered under increased pressure in a specially designed chamber. Hyperbaric oxygen increases the oxygen content in the blood and in different body tissues. It is an accepted therapy for some medical conditions, including burns, decompression sickness, severe infections, radiation-induced tissue injury, and carbon monoxide poisoning. Some people with MS report benefits from using this type of treatment. There have been a number of clinical trials examining the effect of hyperbaric oxygen in MS. Reviews of these studies indicate that there is no beneficial effect.^{46, 47} Based on this, the NICE Guideline for MS, which sets standards for treatment in the NHS, recommends that hyperbaric oxygen is not used.¹⁴ Usually hyperbaric oxygen does not cause serious side effects, though mild visual symptoms may occur. On rare occasions it can cause serious adverse effects, including collapsed lungs, pressure injury to the ear, cataracts, and seizures.

Low dose naltrexone

Naltrexone is an oral medication that is approved in the UK for the treatment of opiate addiction. A typical dose for these purposes is 50 milligrams daily. It has been suggested that naltrexone in low doses, ranging from 1.5 to 4.5 milligrams daily, may be a helpful therapy for people with MS.⁴⁸ There are many anecdotal claims to suggest that LDN is beneficial to people with MS, however currently there is not enough evidence based information to support such claims. The Italian MS Society is currently working in conjunction with researchers on a trial where LDN has been shown, so far, to be a safe treatment for people with PPMS. Results regarding LDN's effectiveness are currently being analysed. There are also other ongoing clinical trials which seek to determine whether the drug is effective. At present in the UK, a GP can only prescribe low dose naltrexone for MS on a 'named patient basis' - explaining that there are unknown risks and any benefits are unproven. Some people may have already been prescribed LDN in the UK, although this is not common. It is also available privately although there are costs associated with this. People are also advised to talk to their GP when thinking of taking any new therapy, so any potential interactions with existing treatments may be discussed.

Magnetic field therapy

The use of magnetic fields as a therapy for MS has been studied mainly with pulsed electromagnetic therapy. This uses devices that emit weak, pulsing electromagnetic fields at a specific frequency. The devices are often placed on acupuncture points. There are many theories about how these devices may be therapeutic. One theory suggests that they may correct disease-associated electrical imbalances and thereby produce acupuncture-like therapeutic effects. However, variable results have been obtained in three clinical trials - though some have shown improvement in spasticity, pain, bladder function, hand function, fatigue, and quality of life.^{49, 50, 51} It is generally believed there is a low risk of side effects associated to weak magnetic field devices. However, pregnant women and those with pacemakers and other implanted electronic medical devices should consult a doctor before using this therapy.

Neural therapy

Neural therapy is a form of energy therapy that was developed in Europe in the 1920s. With this therapy, small amounts of local anaesthetic are injected under the skin in specific locations. The sites of injection may be acupuncture points or old scars. This procedure is thought to restore the normal flow of energy in the body or provide energy to damaged tissue. One small study of neural therapy in people with MS found that there was improvement in about two-thirds of people, and the improvement occurred within minutes of the injections.⁵² Larger and more rigorous studies of the effects of this therapy in people with MS are needed to back up these results. Meanwhile, neural therapy is generally thought to be well tolerated. Repeated injections may cause scarring, and the local anaesthetic may produce allergic reactions.

Replacement of mercury amalgam fillings

It has been proposed that the removal of dental amalgam is therapeutic for MS. Amalgam, which is composed of mercury as well as silver, copper, tin, and zinc, is used in 80 to 90 per cent of tooth restorations. It is claimed that the immune system and nervous system are damaged by small amounts of solid mercury and mercury vapour that is released from the amalgam. There is no evidence that mercury causes MS or that the removal of dental amalgam improves the course of MS.² It has been estimated that amalgam accounts for ten per cent or less of mercury intake. Dental amalgam removal is generally expensive, though there are few risks associated with it. On rare occasions it may cause injury to nerves or tooth structure.

Transcutaneous nerve stimulation

Transcutaneous electrical nerve stimulation (known as 'TENS' for short) refers to the stimulation of a nerve through the application of an electrical impulse to the skin overlying the nerve. TENS is also sometimes applied to acupuncture sites. In this situation, it is similar to electro-acupuncture.

In MS, TENS is typically used to treat pain, but it has undergone limited investigation. A reduction in spasticity has been seen in small studies in MS.^{53, 54} These studies are difficult to interpret since they did not include a placebo-treated group. Again further research is needed to back up these results. TENS is usually well tolerated by people with MS.

Nutrition and dietary supplements

A separate MS Society publication *Diet and nutrition* includes detailed information on dietary supplements, fatty acids (including linoleic acid and fish oils), antioxidants, vitamins and minerals. Cranberry supplements are covered in the MS Society publication *Managing bladder problems* and St John's Wort is covered in the MS Society publication *Mood, depression and emotions*.

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 Freephone MS Helpline offers information and support to anyone with MS, their families, friends and carers. Trained Helpline staff can answer questions about MS and related personal issues. All calls are treated in complete confidence. Information about MS is available in 150 different languages by speaking to a Helpline worker via an interpreter. Freephone 0808 800 8000 (Monday to Friday, 9am-9pm).

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 320 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.

Further reading

The following **books** can give you more information on complementary and alternative medicines:

- Polman, C. *et al. MS: The guide to treatment and management*, 2006, Publisher: Demos Medical Publishing, ISBN: 1932603514
- Bowling, A. *Alternative medicine and multiple sclerosis*, 2001, Publisher: Demos Medical Publishing, ISBN: 1888799528
- Bowling, A. and Stewart, T. *Dietary Supplements and Multiple Sclerosis: A Health Professional's Guide*, 2004, Publisher: Demos Medical Publishing, ISBN: 1888799900
- Pinder, M. *Complementary health care: a guide for patients*, 2005, The Prince of Wales' Foundation for Integrated Health, ISBN: 0953945383
- Barnett, H. *Which? Guide to Complementary Therapies*, 2002, Publisher: Which? Books, ISBN: 0852028938
- Ernst, E. (editor) *The Desktop Guide to Complementary and Alternative Medicine*, 2001, Publisher: Mosby, ISBN: 0723432074

The following **websites** can also provide useful information:

- The US National Center for Complementary and Alternative Medicine examines scientific evidence for the use of complementary and alternative medicines with the aim of disseminating authoritative information to the public and professionals. Their website has useful information about treating specific conditions and symptoms.
www.nccam.nih.gov
- The MS-CAM website of the Rocky Mountain MS Center aims to provide accurate, unbiased, and up-to-date information about complementary and alternative medicine and MS. It also includes information about other non-standard therapies often promoted to people with MS.
www.ms-cam.org

Useful organisations

ASA

If you would like to make a complaint about an advertisement.

Advertising Standards Authority
Mid City Place
71 High Holborn
London WC1V 6QT

Telephone 020 7492 2222
www.asa.org.uk

Action Against Medical Accidents

Independent charity that can provide advice about medical safety and advice if you have experience harm as a result of treatment or failure to treat appropriately.

44 High Street
Croydon
Surrey CR0 1YB

Helpline 0845 123 2352
www.avma.org.uk

Acupuncture Association of Chartered Physiotherapists

For physiotherapists who use acupuncture as part of their treatment.

AACP Limited
Southgate House
Southgate Park
Bakewell Road
Orton Southgate
Peterborough PE2 6YS

Telephone 01733 390007
www.aacp.uk.com

British Academy of Western Medical Acupuncture

For doctors, nurses and physiotherapists who also practice acupuncture.

76 Langdale Road
Bebington
Wirral CH63 3AW

Telephone 01747 861151
www.bawma.co.uk

British Acupuncture Council

Professional organisation for traditional acupuncture practitioners.

63 Jeddo Road
London W12 9HQ

Telephone 020 8735 0400
www.acupuncture.org.uk

British Council for Yoga Therapy

Umbrella group for over 10 UK yoga organisations which can provide details of member organisations and information about yoga.

www.britishcouncilforyogatherapy.org.uk

British Homeopathic Association

Offers information on homeopathy to the public and health care professionals, and can provide lists of medically qualified homeopaths in specific areas of the UK.

Hahnemann House
29 Park Street West
Luton LU1 3BE

Telephone 0870 444 3950
www.trusthomeopathy.org

British Medical Acupuncture Society

For medical practitioners who also practise acupuncture.

BMAS House
3 Winnington Court
Northwich
Cheshire CW8 1AQ

Telephone 01606 786 782
www.medical-acupuncture.org.uk

The European Herbal Practitioners Association (EHPA)

The EHPA is an umbrella body for professional herbal associations, and represents practitioners from Ayurveda, Chinese, Tibetan and Western herbal medicine.

25 Lincoln Close
Tewkesbury
Gloucestershire GL20 5TY

Telephone 01684 291605
www.ehpa.eu

General Chiropractic Council

Regulates UK chiropractors and can provide lists of local practitioners.

44 Wicklow Street
London WC1X 9HL

Telephone 020 7713 5155
www.gcc-uk.org

General Council for Massage Therapy

27 Old Gloucester Street
London WC1N 3XX

Telephone 0870 850 4452
www.gcmt.org.uk

General Osteopathic Council

Regulates UK osteopaths and can provide lists of local practitioners.

Osteopathy House
176 Tower Bridge Road
London SE1 3LU

Telephone 020 7357 6655
www.osteopathy.org.uk

General Shiatsu Council

This group represents a number of the Shiatsu organisations.

Glebe Cottage
Holywell Road
Castle Bytham
Grantham NG33 4SL

Telephone 01780 410072
www.generalshiatsucouncil.org

MS Therapy Centres

A group of self-help centres offering a wide range of drug-free symptom management therapies.

Bradbury House
155 Barkers Lane
Bedford MK41 9RX

Telephone 01234 325781
www.ms-selfhelp.org

NHS Direct

Provides telephone and online advice about NHS services and health.

Telephone 0845 4647
www.nhsdirect.nhs.uk

Reflexology Forum

Umbrella group for UK based reflexology organisations.

Dalton House
60 Windsor Avenue
London SW19 2RR

Telephone 0800 037 0130
www.reflexologyforum.org

Research Council for Complementary Medicine

Aims to develop the evidence base for complementary medicine and provide information about its use to treat specific conditions, including MS.

c/o 1 Harley Street
London W1G 9QD

info@rccm.org.uk
www.rccm.org.uk

Society of Homeopaths

Provides information about homeopathy and lists of homeopaths.

11 Brookfield
Duncan Close
Moulton Park
Northampton NN3 6WL

Telephone 0845 450 6611
www.homeopathy-soh.org

The Aromatherapy Council

Can provide information about aromatherapy and lists of practitioners.

PO Box 6522
Desborough
Kettering
Northants NN14 2YX

Telephone 0870 774 3477
www.aromatherapycouncil.org

The Society of Teachers of the Alexander Technique

Can provide information and details of local practitioners.

1st Floor, Linton House
39-51 Highgate Road
London NW5 1RS

Telephone 020 7482 5135
www.stat.org.uk

WITNESS – Against Abuse by Health and Care Workers

Can offer advice to people who have been abused
by health or social care workers.

Delta House
32-36 Loman Street
London SE1 0EE

Telephone 08454 500 300
www.popan.org.uk

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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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Multiple Sclerosis Society

Multiple sclerosis (MS) is the most common disabling neurological disorder among young adults and around 85,000 people in the UK have MS. MS is the result of damage to myelin – a protective sheath surrounding nerve fibres of the central nervous system. When myelin is damaged, this 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 40 vital MS research projects in the UK.

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
Ratho Park
88 Glasgow Road
Ratho Station
Newbridge EH28 8PP
Telephone 0131 335 4050

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

MS Society, Northern Ireland
The Resource Centre
34 Annadale Avenue
Belfast BT7 3JJ
Telephone 028 9080 2802

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

www.mssociety.org.uk
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