MS
Multiple Sclerosis Society

How to campaign for...

access to FES

Functional Electrical Stimulation

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"I am delighted that the MS Society is providing these resources to help patients access treatments recommended by NICE. The MS Society has helped support the implementation of our guidance since 2004 when they launched the audit support for the multiple sclerosis guideline. We are really pleased that we can continue to work together to keep patients and their carers informed about the treatments we recommend."

Professor Peter Littlejohns, Clinical and Public Health Director, National Institute for Health and Clinical Excellence (NICE), December 2009

"The MS Society works in partnership with people with MS to push for access to effective treatments and services. Access to FES can help people with MS to stay independent; in some cases, it can mean the difference between being able to continue walking and needing a wheelchair. I hope that this guide will give you the information you need to make sure that you get what you are entitled to from your local NHS and challenge local decision makers."

Simon Gillespie, Chief Executive of the MS Society

Executive summary

Functional Electrical Stimulation (FES) is a non invasive device that can help some people with MS to walk. This is a guide to accessing FES, what to do if you are refused NHS funding for FES and then how to get loud!

What is FES?

Functional Electrical Stimulation (FES) is a technique that uses electrical current to stimulate nerves and move parts of the body. FES can help with dropped foot, a symptom of MS, by stimulating the muscles that lift the foot when walking. This makes walking easier and makes it less likely that you will trip or fall.

What do the experts say about FES and MS?

There are around 100,000 people in the UK with MS and over the course of their condition about 75 per cent will experience mobility problems. There is growing evidence to suggest that FES can benefit many people with MS. Research suggests that FES improves walking speed and reduces walking effort in people with MS who experience dropped foot.

Am I entitled to FES?

If you have been recommended for treatment of dropped foot with FES by a neuro-physiotherapist or other health care professional, you should be able to access FES on the NHS no matter where you live in the UK. The National Institute for Health and Clinical Excellence (NICE) has published guidance on FES, demonstrating the safety and efficacy of the treatment. The NICE clinical guidelines on MS, the National Service Framework for Long-term Conditions and the NHS Constitution also support your entitlement to treatments such as FES.

Where is FES available?

Not all health authorities provide FES services or have sufficient funds to allow adequate training of staff to set up and monitor people using FES.

Please note, the term “health authority” is used throughout this document to refer to Primary Care Trust, NHS Board, Health Board, or NHS Trust, each of which is applicable in different parts of the UK.

Your doctor, physiotherapist or MS nurse should, however, be able to refer you to an appropriate service, where a health professional trained in using this equipment can discuss the options with you.

How can I get my FES treatment funded?

FES usually falls outside the range of services and treatments that a health authority has agreed to commission on a routine basis. The NICE guidance is of the type that puts the NHS under no formal obligation to fund the treatment. For this reason, in order to have your FES funded, an individual funding request usually has to be made to the health authority on your behalf. The request should be made by your doctor or physiotherapist and supported with as much information as possible about why FES will be beneficial for you.

What should I do if my health authority refuses to fund my FES treatment?

If your request for funding is refused, you may wish to appeal the decision. It is a good idea to discuss this with your doctor or physiotherapist before going ahead with the appeal. If your request is turned down after an appeal, there are still ways in which you can challenge your health authority's decision: there may be grounds to start a local campaign in your area; you could share your story with the local press; or you might wish to write to your MP. If you have appealed and you are not happy with the process that was used to arrive at a decision, you can submit a formal complaint to your local health authority.

Inspiration from others

In this guide, you can read about the experiences of other people with MS who have campaigned successfully for access to FES. It is important to remember that everyone's experience will be different and there are many different ways to campaign on this issue. The following essential campaigning tips provided by our three FES campaigners will come in handy for your own campaign:

- ✔ **Do your homework – reading this guide will give you a good start in finding out everything you need to know about FES.**
- ✔ **Keep a positive attitude with the people. you are dealing with – it's important to keep people on your side.**
- ✔ **Seek support from others.**
- ✔ **Keep records of names, dates and telephone numbers and keep all your paperwork in one place.**
- ✔ **Don't be afraid to copy and paste information from this guide to use in your campaign.**
- ✔ **Don't give up!**

Get in touch and join the Campaigns Network

If you use this guide to campaign for FES, then please tell us about your experiences. We want to hear about your successes and your trials and tribulations therefore please email us on campaigns@mssociety.org.uk or phone the Policy and Campaigns team at the MS National Centre on 020 8438 0700.

If you would like to keep up to date with the work of the Policy and Campaigns team and find out what local campaigners are achieving near you, then join over 7000 other people affected by MS by signing up to the Campaigns Network here: http://www.mssociety.org.uk/campaignsnetwork.

What is the evidence?

Introduction

This guide has been written for people affected by MS who:

- **want to find out more about Functional Electrical Stimulation (FES);**
- **have been recommended FES by a consultant, MS nurse specialist or health care professional such as a neuro-physiotherapist, occupational therapist or orthotist; or**
- **have been refused NHS funding for FES.**

In clarifying the guidance on FES from the National Institute for Health and Clinical Excellence (NICE), this guide will help to ensure you get what you are entitled to from the NHS.

What is FES?

Functional electrical stimulation (FES) is a technique that uses low levels of electrical current to stimulate nerves. This can help to move parts of the body that have been affected by spinal cord injury, head injury, stroke or other neurological conditions such as MS.

The technique involves attaching electrodes (similar to self-adhesive patches) to the surface of the skin. These transmit small electrical impulses to stimulate the nerves and activate the muscles. The most common problem treated by FES is called dropped foot (sometimes 'drop foot').

People with MS experience dropped foot when they cannot smoothly control the foot's actions during walking. This can make walking more difficult and increase the risk of trips and falls. People with MS can experience dropped foot on one or both legs.

FES can help with dropped foot by stimulating the muscles that lift the foot during walking. A switch worn in the shoe, or a sensor in the stimulator that detects leg position, triggers the stimulation. The electrical signals reach the nerve through electrodes stuck to the skin over the area closest to the nerve pathway on one side of the leg, just behind and below the knee. Some stimulators are the size of a pack of cards and can be worn at the waist on a belt or in a pocket. Other stimulators take the form of a specially designed cuff placed below the knee with a wireless control unit. The FES system may or may not require leads to connect the stimulator to the switch in the shoe and to the electrodes on the leg. A small regular or rechargeable battery operates the stimulator.

What do the experts say about FES and MS?

There are around 100,000 people in the UK with MS and over the course of their condition about 75 per cent will experience mobility problems. There is growing evidence to suggest that FES can benefit many people with MS. This includes two recent small clinical trials investigating the effects of FES on walking speed and ability in people with MS (Paul, Rafferty et al 2008 and Barrett, Mann et al 2009). Both trials suggest that FES improves walking speed and reduces walking effort in people with MS who experience dropped foot.

One of the trials compared the effects of FES with therapeutic exercise (Barrett, Mann et al 2009). Walking speed, walking effort and average distance walked were all significantly improved in people using FES. Results from this trial suggested that FES may be of benefit to people with MS who are currently not offered any treatment, but that therapeutic exercise is better at improving walking speed and ability. The trial concludes that therapeutic exercise in combination with FES may be more beneficial in people with MS than either treatment alone.

The most recent study published looking at the effects of FES in people with progressive forms of MS showed that FES was able to improve walking speed by 13.1 per cent and decrease walking effort by 6.5 per cent (Stein, Everaert et al 2009).

These studies reinforce data from previous studies that show that a particular FES device called an Odstock Dropped Foot Stimulator is beneficial to people with dropped foot (Burridge, Taylor et al 1997, Taylor, Burridge et al 1999a and Taylor, Burridge et al 1999b). These studies are larger studies that investigate a number of people with different conditions who experienced dropped foot including people with MS.

More work is ongoing to determine the exact benefit of FES to people with MS, but there is clear evidence that FES helps to improve walking speed and decrease walking effort in a number of conditions, including spinal cord injury, stroke, and MS.

There is also considerable evidence published about the safety of FES in people with MS. Some people discontinued the device after a period of time because of minor skin irritations or spasticity in the calf muscle, but most users benefited from using FES. The major reason for discontinuing use in one study was due to improvements in mobility for people who have had a stroke (Taylor, Burridge et al 1999b).

There is a more detailed summary of FES research for people with MS in the appendix at the end of this document.

Am I entitled to FES?

If you have been recommended for treatment of dropped foot with FES by a neuro-physiotherapist or other health care professional, you should be able to access FES on the NHS no matter where you live in the UK.

Under no circumstances can any health authority have a blanket ban on funding FES.

Health authorities can opt not to routinely fund FES, but they are obliged to consider whether you are an exceptional case and whether you should therefore have your FES funded by the NHS.

The National Institute for Health and Clinical Excellence (NICE) has published guidance on FES. NICE is an independent organisation responsible for producing guidance which sets the standards for good health care so that everyone gets the same high quality care. Based on the clinical and cost effectiveness of a given treatment or intervention, NICE develops different types of guidance to inform decisions about what patients can expect to access on the NHS, including FES.

The NICE guidance on FES has been categorised as ‘interventional procedure’ guidance, which assesses the safety and efficacy of a procedure. This means that, unlike other forms of NICE guidance such as a ‘technology appraisal’, it is not mandatory for local health authorities to fund the treatment. It is possible, however, to use the guidance and other national policies to support your entitlement to FES as the next section will explain.

Which NICE guidance applies?

NICE produces different types of guidance. The type of guidance determines where it applies in the UK.

Scotland
- Technology appraisals
- Interventional procedures

England
- Clinical guidelines
- Technology appraisals
- Interventional procedures
- Public health guidance

Wales
- Clinical guidelines
- Technology appraisals
- Interventional procedures

Northern Ireland
- Technology appraisals
- Interventional procedures

(source: http://www.nice.org.uk/media/888/38/ourguidancesetsstandard.pdf)

What does NICE say about FES?

NICE produces different types of guidance. The type of guidance determines where it is implemented in the UK.

NICE published interventional procedure guidance (IPG278) entitled *Functional electrical stimulation for drop foot of central neurological origin* on 28 January 2009. The guidance states the following:

> 1.1 Current evidence on the safety and efficacy (in terms of improving gait) of functional electrical stimulation (FES) for drop foot of central neurological origin appears adequate to support the use of this procedure provided that normal arrangements are in place for clinical governance, consent and audit.
>
> 1.2 Patient selection for implantable FES for drop foot of central neurological origin should involve a multidisciplinary team specialising in rehabilitation.
>
> 1.3 Further publication on the efficacy of FES would be useful, specifically including patient-reported outcomes, such as quality of life and activities of daily living, and these outcomes should be examined in different ethnic and socioeconomic groups.

The accompanying NICE publication for patients states the following:

"This procedure can be offered routinely as a treatment option for people with drop foot caused by damage to the brain or spinal cord, provided that doctors are sure that:

- the patient understands what is involved and agrees to the treatment
- the results of the procedure are monitored."

To see the full published guidance and a version of the guidance written specifically for patients and carers, please visit the NICE website – **http://www.nice.org.uk/guidance/IPG278**

What do other key policy documents say?

In addition to publishing guidance specifically on FES, NICE published a set of **clinical guidelines on the management of MS** in 2003. These guidelines are also of key relevance here. The guidance states that:

"Physiotherapy treatments aimed at improving walking should be offered to a person with MS who is, or could be, walking" (section 1.6.4.2).

"If a person with MS depends on someone else for an activity (especially in mobility), an expert should assess whether an aid or adaptation… could be of benefit. For example, it may increase the independence of the person with MS, and/or minimise the stress on, or risk for, the person who assists them" (section 1.6.6.2).

The guidelines also state that people with MS should have access to a service which includes "identifying and treating any treatable underlying impairments" and "providing suitable equipment with training in its use" (section 1.6.1.3). FES is a useful constituent of such a service as it restores movement, improves walking ability and reduces a very disabling aspect of MS – fatigue.

The **National Service Framework for Long-term Conditions** (NSF), which was published by the Department of Health in 2005, states that people with long-term neurological conditions should receive:

"timely, appropriate assistive technology/equipment…to support them to live independently; help them with their care; maintain their health and improve their quality of life".

The NSF gave commissioners (the people responsible for purchasing services) and providers up to 10 years to implement fully its recommendations.

The NHS therefore has an obligation to make sure that people with MS have access to technologies such as FES, which can significantly improve walking ability, increase people's level of independence and enhance their quality of life.

The **NHS Constitution**, published in January 2009, states that everyone should have the right to expect local decisions on treatments to be "made rationally following a proper consultation of the evidence." It goes on to say that, if the local NHS decides not to fund a treatment you and your doctor feel would be right for you, they will explain that decision to you.

What does this mean for me?

Although FES has been recommended by NICE in its interventional procedures guidance – which means it is both safe and efficient to use on the NHS – health authorities are under no obligation to fund it. Decisions about funding are instead taken by local NHS bodies after considering how well the procedure works, whether it represents value for money for the local NHS and whether there is adequate local expertise in performing the procedure.

FES is therefore not routinely funded despite its relatively low cost to the NHS and the independence it can give to people with MS who experience dropped foot. The treatment is still considered a low priority by many health authorities and therefore access to FES varies across the UK.

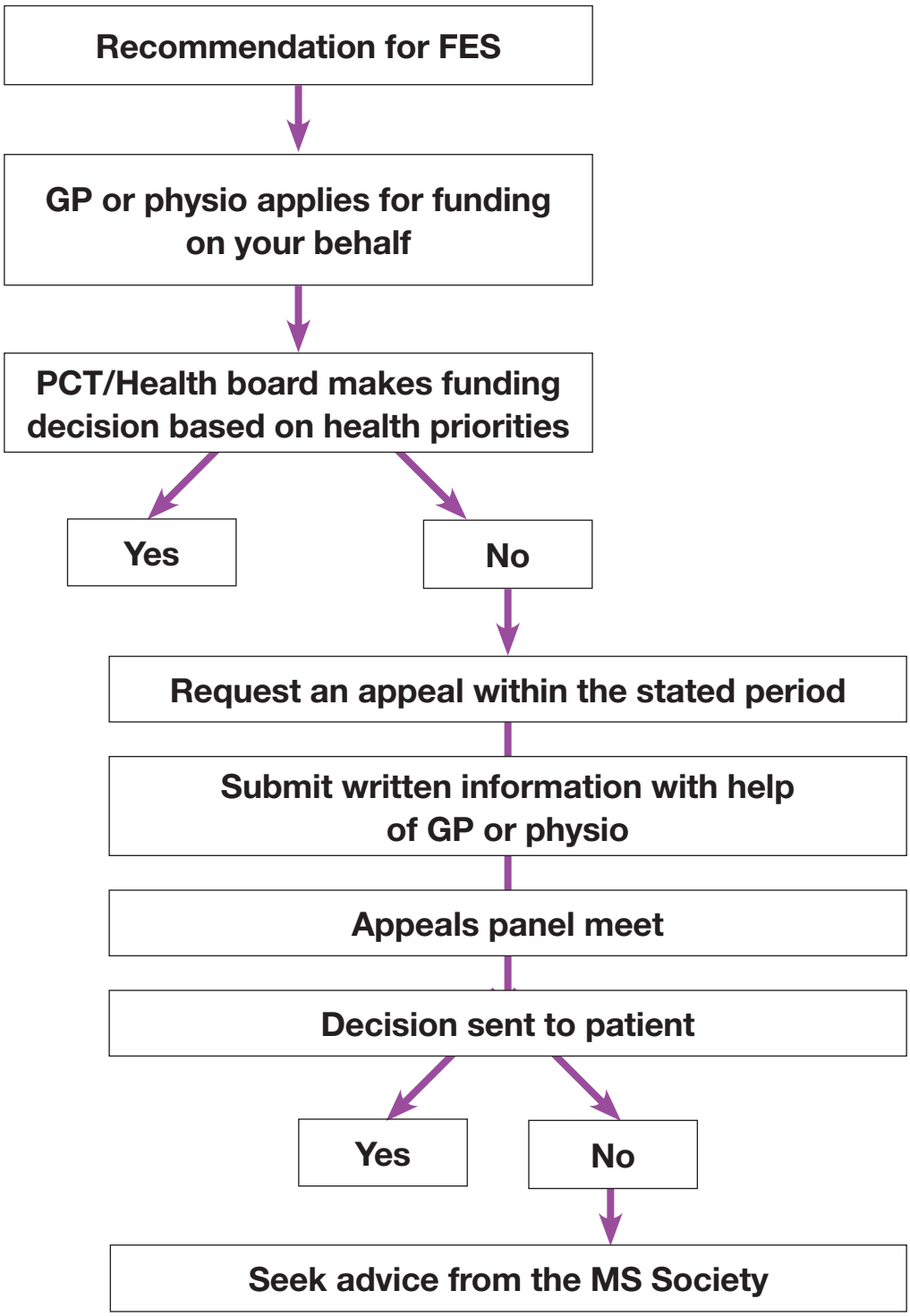
Looking on the bright side, however, the fact that there is NICE guidance available means that **health authorities cannot refuse to fund FES on the grounds of a lack of evidence.** NICE would not have been able to assess or approve the treatment if there was a lack of evidence.

How do I get FES?

Accessing FES: timeline

Approximately 2 to 3 months

Approximately 2 to 3 months



Where is FES available?

Not all health authorities provide FES services or have sufficient funds to allow adequate training of staff to set up and monitor people using FES. Your doctor, physiotherapist or MS nurse should, however, be able to refer you to an appropriate service, where a health professional trained in using this equipment can discuss the options with you.

There are various companies that provide FES systems for people with MS. The National FES Centre in Salisbury handles the majority of enquiries relating to FES. As well as serving the area surrounding Salisbury, they also have a number of outreach clinics around the UK, to which they can refer you. Enquiries should be directed to enquiries@odstockmedical.com or 01722 429065.

The largest outreach FES service is in Birmingham at the West Midlands Rehabilitation Centre. Please contact christine.singleton@sbpct.nhs.uk or telephone 01216 278129 for further details.

A new FES clinic has also recently been set up at the BrAMS (Bristol and Avon MS) Centre at Frenchay Hospital in Bristol, using a different type of stimulator and specialising in the treatment of dropped foot in MS. Please contact Angela.Davies-Smith@nbt.nhs.uk for further details about the clinic.

In order to give you some idea of the location of FES clinics, here is a list of them and the areas they cover:

FES clinics and areas covered

Salisbury
Areas covered:
East Sussex
West Sussex
Kent
Wiltshire
Dorset
Hampshire
Somerset

Bristol and Avon
Areas covered:
South Gloucestershire
Bristol
North Somerset
Bath and NE Somerset

Cornwall and Devon
Areas covered:
Cornwall and Isles of Scilly
Plymouth
Devon

Hertfordshire
Areas covered:
Hertfordshire and surrounding areas
Essex
North London

East Anglia
Areas covered:
Cambridge
Lincolnshire
Suffolk
Norfolk
Peterborough

Functional Electrical Stimulation (FES)

Northamptonshire
Areas covered:
Northampton
Leicestershire
Bedfordshire
Milton Keynes
Oxford
Buckinghamshire

West Midlands
Areas covered:
Birmigham
Coventry and Warwick
Staffordshire
Worcestershire
Black Country

Yorkshire
Areas covered:
Harrogate
Yorkshire and York
East Yorkshire
Leeds
Bradford

Lancashire
Areas covered:
The North West (including Manchester)

North East
Areas covered:
Newcastle upon Tyne and surrounding areas

Scotland
There are satellite clinics held in Glasgow every three to four months for Scottish patients. Referrals in Scotland can also be made to the Western General Hospital and the McLeod Street Physiotherapy Clinic in Edinburgh.

In addition to the centres listed above, there are a number of independent FES centres across the UK. The main areas covered are as follows:

Independent FES Centres
Birmingham
Sheffield
Leeds
London (Roehampton and Whitechapel)
Shropshire
Middlesex
Berkshire
Cardiff
Swansea
Lothian
Ayrshire and Arran

What does an assessment involve?

Before using FES, you need to be assessed to determine whether it is suitable and beneficial for you. You will normally be invited to attend a hospital clinic or physiotherapy department for your assessment. Some of the medical outreach clinics can offer home visits for your assessment. You will usually be seen by a neuro-physiotherapist (a physiotherapist who specialises in treating patients with neurological conditions such as MS). You may, however, be assessed by an orthotist or medical engineer/scientist instead.

The clinician who is carrying out your assessment will first explain the procedure to you. You will be asked to demonstrate walking, usually with and without your walking aid or splint, so that the clinician can build up a detailed clinical picture of your walking and plan the assessment.
After assessing how tight your calf muscles are and whether you have the appropriate range of movement in your ankle, your clinician will attempt to position the FES equipment where it produces the required movement with the most comfortable level of stimulation for you. Typically, one electrode will be positioned on the outside edge of your upper calf just below the knee and the other just below but nearer to the front of your shin. Sometimes, the electrodes will need to be repositioned to give the desired result.

Your clinician will assess how the equipment helps your walking by triggering the equipment manually as you walk and adjusting the settings to best suit you. When the clinician is satisfied with this, he or she will put a heel switch under your foot which will automatically trigger the device to help you walk. The switch is stuck onto a removable insole that can be swapped between different pairs of shoes.

Your clinician will thoroughly explain and teach you how to use the FES. You will be advised how long to wear the device for in the first few days and what to look out for. It may seem daunting at your first assessment, but as with most new things, you will very quickly learn how to use your FES and you will soon be enjoying the benefits FES has brought to so many users.

Far left: Paddy Rozier, who has bilateral footdrop as a result of MS, is assessed for FES by Jon Graham, Clinical Director of Physiofunction, at the Beyond Boundaries event in 2009.
Left: Jon adjusts the FES equipment for Paddy

How can I get my FES treatment funded?

FES usually falls outside the range of services and treatments that a health authority has agreed to commission on a routine basis. It is considered as a low priority by most health authorities and the NICE interventional procedures guidance, unlike the technology appraisal guidance (see section on NICE), puts them under no obligation to fund the treatment. For this reason, in order to have your FES funded, an individual funding request usually has to be made to the health authority on your behalf.

Making a funding request

Requests for funding should be made by your doctor or physiotherapist and supported with as much information as possible about why the treatment will be beneficial for you. Although each health authority does this slightly differently, it is likely to assess the request in terms of three key questions:

- Is there evidence that the treatment works?
- Are there national standards or guidance saying that the treatment should be offered?
- Is the treatment cost effective?

Your doctor or physiotherapist should explain to your health authority what the expected outcome would be for a patient with MS and ask for funding to assess your suitability for FES with the promise of a report on the outcome and the benefits. Safety (reduction in tripping and falling), and improved quality of life and participation in society are good areas to highlight to the health authority. Cost benefits are also useful to highlight – these could include the reduced cost of treating fractures caused by falls and reducing the need for carer support due to increased independence.

If you have already had an FES assessment, your doctor or physiotherapist should also be able to provide specific evidence relating to the benefit of FES for you. This could include, for example, a video gait analysis – using a video to measure and analyse the biomechanics of your feet and legs as you walk on a treadmill – or objective measurements of improved walking speed, step length and reduced number of falls. Some stimulators provide this information as part of their function.

"Exceptional circumstances"

Sometimes, a request will only be considered for "exceptional circumstances", so you will be required to demonstrate "exceptionality" in your individual case. In these circumstances, it needs to be demonstrated that you are significantly different from the general population of patients with the condition in question and that you are likely to gain significantly more benefit from the intervention than might normally be expected for patients with that condition. Lifestyle factors are important here – for example, it might be the case that you have a young family so you need to be mobile and safe around the house to look after them. This is just one example but many other factors could be taken into account.

FES is not effective for everyone and it will not be suitable for all people with MS, especially those with ataxic symptoms. This is why it is so important to show in your funding request why you and your doctor think FES will be effective for you and that it will significantly improve your walking ability, ability to work and quality of life to a greater extent than for the general population of people with MS.

You should also make sure that whoever submits the request for you includes information from the earlier section of this guide, detailing the NICE guidance, and from this guide's appendix, detailing wider

research findings in support of FES.

Cost effectiveness

It is worth noting that FES is a relatively cheap treatment compared to most things that are routinely funded by the NHS. It is also a sound intervention for many who are no longer eligible for new drug trials or ongoing disease modifying treatments. The costs that need to be taken into account for FES include those for treatment sessions (there are usually three to six of these in the first year of use), the FES equipment itself, resources, overheads and VAT. While costs will vary depending on the type of stimulator that is used, and other factors, the following estimate can be used as a guide. This may be useful when approaching your health authority for funding so they can see a breakdown of the estimated costs involved:

- Assessment: from £75/hour
  (initial assessment usually takes 1-2 hrs)
- Equipment and fitting: £600-700
  (usually takes 2 hours)
- 6 week review: from £75/hour
  (review usually takes an hour)
- 3 monthly reviews: from £75/hour
  (review usually takes an hour)

Estimated initial annual total: £975-1450

Estimated annual follow up: £300-600

Please note, this is simply an estimate. Costs and frequency of reviews will depend on the type of stimulator being used.

Who considers the funding request?

Your request for NHS funding will usually be considered by a panel, the name of which will depend on the internal structures that are in place. Harrow PCT, for example, processes requests through what is called the "Individual Treatment Panel" while in Derbyshire this is referred to as the "Non Contract Treatment Panel". Once the panel has considered the request, a letter will usually be sent to you and your doctor communicating the panel's decision and their reasons for making this decision.

Funding FES privately

FES can be funded privately if you wish, but we would recommend that your treatment should be funded by the NHS.

It is worth noting that, should you choose to fund FES privately, you will sometimes have to pay VAT on top of the equipment costs. Disabled people are usually eligible for VAT relief on goods specially designed or adapted to suit their condition. However, for goods that are supplied to a person attending a hospital for care or treatment, VAT zero rating does not apply. As FES equipment sometimes has to be fitted at a hospital, it is not always zero-rated. This is a good reason for making sure that your FES treatment is funded by the NHS. More details on VAT relief for disabled people is available from the HM Revenue and Customs website – **http://www.hmrc.gov.uk**

If you are considering private funding, you may be interested to know that wireless FES units (Walkaide and Bioness L300) are available in addition to the wired FES models that are currently provided by the NHS. The technology for wireless FES is considerably more expensive than the wired version; the Walkaide can be supplied for approximately £2000 and the Bioness L300 is approximately £4000 plus VAT. (The price for the Bioness L300 includes six to eight therapy visits and one year of electrodes.) Clinics will sometimes offer a free initial assessment following a referral from a GP or consultant. Please contact **info@trulife.com** for further details about the Walkaide or **info@uk.bioness.com** for details about the Bioness L300.

What should I do if my health authority refuses to fund my FES treatment?

Your health authority may refuse to fund your FES treatment. There are additional steps you can take at this stage to try to make the health authority review its decision. This section explains what you can do in this situation.

How does the appeals system work?

If your request for funding is refused, you may wish to appeal the decision. It is a good idea to discuss this with your doctor or physiotherapist before going ahead with the appeal.

If you decide to make an appeal, you should take note of the following points:

1. Make sure you know how your health authority's appeals process works. This will vary depending on where you live. Details of the process should be available on request from the health authority – the person who sent you the refusal letter should be able to help with this. The process might also be available from the health authority's website.

2. Make sure that you appeal the decision within the specified number of days after receipt of the refusal letter otherwise your health authority has the right not to consider your appeal. The time limit should be stated clearly in the refusal letter. If no time limit is specified, it is advisable to check this with your health authority.

3. When you are invited by the appeal panel to submit written evidence in support of your case, your treating clinician will usually provide most of the evidence. However, there should be an opportunity for you to add to this with any other information which you feel might be relevant to your case. Make sure you include as much information as possible about why you think FES will be beneficial for you.

4. If you are invited to make an oral representation to the panel to supplement a written statement, you should take up the opportunity if you feel it would strengthen your appeal. Equally though, you should not feel under any pressure to appear before the panel if you think this might cause you additional stress or anxiety. The panel may allow someone else to make the presentation on your behalf. The Independent Complaints Advocacy Service (ICAS) might be able to help you with your appeal (see further details at the end of the guide).

5. Health authorities vary in how often their appeals panels meet. For example, some meet once a month while others meet once a quarter. The panel will usually be a group of people who had no involvement in your original request for funding.

6. The panel's decision should be communicated to you in a letter shortly after the meeting to discuss your case. The panel is obliged to give you a clear explanation of how it reached its decision.

When going through the appeals process remember to stay positive and to keep persevering. The case studies in the next section of this guide should help to provide you with some inspiration and tips for success. Good luck and don't give up!

How to get loud!

If your appeal for funding is refused, there are still ways in which you can challenge your health authority's decision.

Involving the Policy and Campaigns team

If accessing FES in your area is proving to be a problem, we want to know about it, so please do get in touch. There may be grounds to start a local campaign in your area and we can help with putting the wheels in motion for this.

The MS Society has five area teams in England and relies on the regional service development officers (SDOs) within these teams to influence local services for people with MS. The Society also has national offices in Scotland, Wales and Northern Ireland. We can put you in touch with your local SDO or national office so that you have access to local support and expertise to help with your campaign.

You can also get in touch with us if you have any general inquiries relating to the information in this guide. If you have reached the end of the appeals process and have been unsuccessful, we can advise you about the next steps to take.

Please call 020 8438 0700 and ask for the Policy and Campaigns team or email us at campaigns@mssociety.org.uk

Involving the local press

If you want to share your story with the press, you should first consider the following:

- In conversation with the Policy and Campaigns team, work out if you have a story the press will want to tell – and whether telling the press is really the best option. We can advise you on the best course of action, which may not always be to involve the media, and we will discuss your case with our Press Office.
- If you are comfortable with the idea and your story does merit media attention, the MS Society Press Office will guide you through the process of contacting the local media, or can do this on your behalf.
- You will have to give out personal details like your name and where you live. You should also be prepared to be photographed. If you are not comfortable with this, then sharing your story is not appropriate.
- By telling your story in the local media, you will be helping to shine the light on a situation that may well be affecting many other people and you will hopefully help change things for the better.

Involving your local MP:

Your local MP might be able to help with influencing your health authority to review its position on funding FES. You can find out who your local MP is by entering your postcode on the parliament website here - http://findyourmp.parliament.uk/ - or by calling the House of Commons Information Office on 020 7219 4272. You can use the template letter below to write to them about your case. Remember to keep your letter concise and to the point.

To copy and paste this letter or to download this letter as a word document, please visit: http://www.mssociety.org.uk/fes

Template MP letter

Your Name
Your Address

MP's Name
House of Commons
London
SW1A 0AA

Date

Dear Mr/Mrs_____

Refusal of funding for Functional Electrical Stimulation

I have recently been refused funding for a treatment called Functional Electrical Stimulation (FES) by _____(insert name of your local PCT/health board).

Insert brief description detailing the following:
- how your MS affects you in terms of walking ability
- how FES will benefit you
- why you don't agree with the decision reached by the PCT/health board
- what steps you have taken so far (eg appeal process)

NICE published interventional procedure guidance for FES on 28 January 2009. The guidance states that current evidence supports the safety and efficacy of this procedure and that the procedure can be offered routinely as a treatment option for people with drop foot caused by damage to the brain or spinal cord.

The case for FES is also supported by NICE's clinical guidelines for MS, which state that: "Physiotherapy treatments aimed at improving walking should be offered to a person with MS who is, or could be, walking" (section 1.6.4.2). The guidelines also state that people with MS should have access to a service which includes "identifying and treating any treatable underlying impairments" and "providing suitable equipment with training in its use" (section 1.6.1.3). FES is a useful constituent of such a service as it restores movement, improves walking ability and reduces a very disabling aspect of MS – fatigue.

I would be grateful if you could raise my concerns with _____ (insert name of PCT/health board) and I look forward to your response.

Yours sincerely,

Your Name

Using the NHS complaints process

If you have appealed a refusal to fund FES and you are not happy with the process that was used to arrive at the decision, you can submit a formal complaint to your local health authority. The health authority is responsible for all NHS services in your local area.

If you have been refused treatment with FES or encountered longer than expected waiting times for treatment with FES, then you reserve the right to complain under the NHS Constitution.

The MS Society has a wealth of experience in helping people with MS to get their complaints dealt with quickly and efficiently. Here are a few handy tips to ensure you get the most out of the complaints process:

Step 1: write to your local Patient Advice and Liaison Service (PALS)

The best way to ensure your complaint is registered as a formal NHS complaint is to fill out the local PALS NHS complaints form. To request a form you first need to find your nearest PALS service. The easiest way to do this is to visit http://www.pals.nhs.uk/officemapsearch.aspx and type in your post code. Here you will be able to view the contact address and telephone number for your local PALS to request a form.

If you wish to alert the chief executive of the Trust to your complaint, you could write a separate letter detailing the specifics of your case. If you choose to write in addition to filling out the PALS form, remember to copy in the PALS manager. You should receive a response in less than 20 working days. If you do not receive a response, please contact the MS Society's Policy and Campaigns team and we can put you in touch with your local MS Society Service Development Officer (SDO).

Step 2: refer your complaint to the Health Service Ombudsman

Only once you have registered your complaint with PALS and/or the local health authority and sought local resolution can you then take your complaint to the Health Service Ombudsman. Please note that the Health Service Ombudsman can only help you if your complaint is about the NHS or NHS funded health care in England.

To make a complaint for the NHS in England, you need to fill out the following form here: http://www.ombudsman.org.uk/documents/health_complaint_form.doc.

The MS Society would advise you to do the following:

- Keep your complaint succinct – only explain what is necessary.
- You may find it helpful to detail events chronologically – this might help with the structure of your complaint.
- Attach any supporting evidence such as letters, emails and any relevant notes to the end of the form.
- Ensure you give the ombudsman permission to access your medical records in order to investigate your complaint.
- Finally, don't forget to include your original letter of complaint and a copy of the "final response" letter to your complaint from the health care provider.

To make a complaint to the ombudsman for one of the devolved areas of the UK, please see the following links:

- **Scotland** – the Scottish Public Services Ombudsman http://www.spso.org.uk/

- **Northern Ireland** – the Northern Ireland Ombudsman
  http://www.ni-ombudsman.org.uk/index.htm

- **Wales** – the Public Services Ombudsman for Wales
  http://www.ombudsman-wales.org.uk/

The ombudsman will review your case before deciding how to proceed with your complaint. If you would like further advice, the helpline telephone number for the Ombudsman in England is: 0345 015 4033

Step 3: seek judicial review

If your complaint has still not been addressed adequately and you feel you may have a legal case, patients reserve the right to seek legal redress through a judicial review.

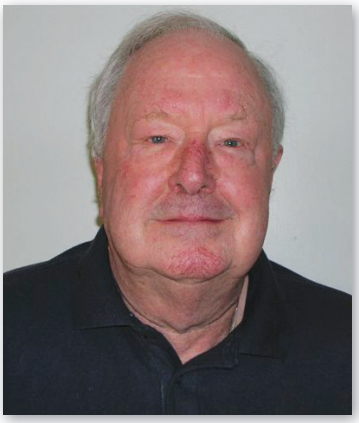
A judicial review is a type of court proceeding in which a judge reviews the lawfulness of a decision or action made by a public body such as a PCT. Judicial reviews are a challenge to the way in which a decision has been made, rather than the rights and wrongs of the conclusion reached and should only be considered as a last resort. You should contact the MS Society's Policy and Campaigns team if this is an option you wish to explore.

Inspiration from others

In this section you can read about the experiences of other people with MS who have campaigned for access to FES.

It is important to remember that everyone's experience will be different and there are many different ways to campaign on this issue.

The essential campaigning tips provided by Cliff, Robin and Ian might come in handy for your own campaign. If these three have been successful, then so can you!



Visit our website for more **inspirational campaigning stories** at www.mssociety.org.uk/campaignsnetwork or **write to us** to tell us about your experiences at campaigns@mssociety.org.uk

Cliff's campaign

Cliff's crusade to get access to FES

Cliff is a member of the Richmond branch of the MS Society. He campaigned for some time to obtain funding for FES from his local PCT in Hounslow. Although FES is not suitable for everyone with MS, for Cliff, who has secondary progressive MS, FES means the difference between being able to continue walking and needing a wheelchair.

How the campaign started

After reading about the potential benefit of FES for the treatment of dropped foot in people with MS, Cliff approached his GP and asked whether he might be eligible for the treatment. He received a somewhat negative response at first due to the fact that his local PCT (Hounslow) did not have a history of funding FES in the past. However, Cliff's physiotherapist agreed to refer him to the National Clinical FES Centre in Salisbury for an assessment.

Unfortunately, due to the cost and logistics of an assessment in Salisbury, Cliff was forced to look into other options closer to home. His physiotherapist referred him to a local hospital which offered FES. Here, he was able to try the FES equipment and assess whether it would be beneficial for him. The assessment concluded that the treatment improved Cliff's walking ability by an incredible 88 per cent.

What happened next?

Convinced that the treatment would be highly beneficial to him, Cliff applied to Hounslow PCT for funding, submitting reports from his physiotherapist and occupational therapist detailing how the treatment benefited him. The PCT rejected both the initial application for funding and Cliff's subsequent appeal on the grounds that there was insufficient statistical evidence to prove the benefits of FES.

Despite this, Cliff refused to give up and made a second appeal to the PCT. This time he submitted a full costings report, which detailed what the treatment would cost the PCT for a five year period, along with follow up reports from his physiotherapist and occupational therapist. As a result of the second appeal, the PCT agreed to fund a six month trial of FES.

As a result of the campaign…

Cliff secured six months funding for FES from the PCT and has recently been granted a further six months funding for the treatment due to the proven positive benefits that he has experienced.

Cliff has also been invited to take part in a research project in which he will act as a case study to demonstrate the benefits of FES for people with MS.

Cliff's campaigning tips

"Charm! Treat people like human beings. Be nice to them. Keep taking it to the next step and get people on your side."

"Get hold of data because it arms you for your campaign."

"Never give up. Whatever hoops they put in your way, just jump through them, and don't take no for an answer."

Robin's campaign

Robin's campaign: access to FES in Gloucestershire

As an ex-journalist, Robin knew what he had to do to hold his Trust to account when they refused to fund FES. In quoting national policy with the support of others, Robin was able to reverse the Trust's decision.

How the campaign started

Robin was assessed for treatment with FES by a neuro-physiotherapist; the assessment confirmed that Robin would benefit from access to FES. A request for funding was then made to Gloucestershire PCT which was refused. In the refusal letter that Robin received, it stated that a lack of evidence to suggest FES was beneficial for people with MS meant that they would not fund the treatment.

What happened next?

After receiving the letter in January 2005, Robin decided to launch a formal complaint to challenge the decision. He did this with the support and involvement of the following people: his neuro-physiotherapist, consultant neurologist, GP, local MS specialist nurse, MP and local MS branch. Robin was also ready to use his experience as a journalist, with the help of newspaper colleagues, to raise awareness of the issue and unmask the unfairness of the situation through local, regional and national newspapers plus radio and television networks. These actions all helped to play a part in holding the Trust to account.

Robin also used national policy to help make his case to the Trust. Quoting the NICE clinical guidelines, he was able to state: "all services and service personnel within the health care sector - should recognise and respond to - the variety and unique needs and expectations of each person with MS" (NICE, 2003: 56). To add extra weight to his argument, Robin made the case that FES does improve walking which in turn helps to reduce levels of fatigue including the risks of tripping and falling.

As a result of the campaign…

In September 2005, Robin was finally told that he could have access to FES on the NHS. It was a long process but his campaign has helped to highlight the improvements in quality of life that FES can offer. For Robin, FES has been a lifeline, helping to increase his confidence and independence.

Robin's campaigning tips

"I would recommend other patients facing a similar dilemma to fight tooth and nail to get funding and to leave no stone unturned."

"It is a harsh and undeniable fact that NHS decisions are ruled by finance rather than clinical need. For me, FES is a lifeline. Walking is still a trial but without FES, I couldn't walk at all. It is a boon, a lifeline – the most marvellous invention ever!"

Ian's campaign

Ian's campaign: access to FES in Derbyshire

Ian has secondary progressive MS and experiences severe difficulty with walking. After being assessed as a suitable candidate for FES, Ian was refused funding for the treatment by his local PCT. Unsatisfied with the PCT's decision, Ian decided to appeal and, after an intense few months, managed to secure funding for his treatment.

How the campaign started

Ian first heard about the benefits of FES treatment at an MS Society meeting in Loughborough. He discussed the treatment with his GP, who then referred Ian to the FES clinic at the Northern General Hospital in Sheffield where he was assessed by a neurological physiotherapist. It was concluded that Ian was a suitable candidate for FES and that it would help him to regain some walking ability.

Having obtained the support of his GP, consultant and neuro-physiotherapist, a request for funding for the treatment was sent to Derbyshire County PCT by Ian's GP in December 2006. Ian received notification from the PCT's Non Contract Treatment Panel in February that the request had been rejected due to the fact that there was a lack of evidence that FES is effective. Clearly unsatisfied with this decision, Ian decided to appeal.

What happened next?

Ian was aware that he would have to supply the PCT with as much information as possible about how FES benefited him in order to reverse the panel's decision. To do this, he put together a dossier of recent research supporting the effectiveness of FES. He sought support from the FES clinic in Sheffield, which was able to supply him with evidence of the positive outcomes of FES in people with MS. Both Ian's physiotherapist and GP also wrote in support of his appeal.

Ian accepted the PCT's invitation for him to attend the meeting and present his evidence in person. He describes this as an intimidating experience but it allowed him to put forward a strong case for his appeal. In making the case, Ian described his improved mobility with FES, his better quality of life and increased confidence. He also stressed the fact that the risk of him falling was greatly reduced. The PCT would therefore be less likely to have to pay for treatment of an injury caused by falling, for example a broken hip, which would cost the NHS and social services far more to treat and would cause Ian added pain and misery.

As a result of the campaign…

The appeal panel wrote to Ian shortly afterwards to inform him that his appeal had been successful. He had satisfied the PCT's "value set" by demonstrating that FES was effective, appropriate and efficient.

Ian's campaigning check-list:

- Do your homework
- Seek support from as many people as you can
- Appeal any refusal
- Go to the appeal armed with information
- Go with someone to support you and to witness the process
- Keep records of names and dates and keep all paperwork in one place

Ian says: **"Don't take no for an answer: it's your body, your life and you have paid your taxes for this!"**

Over to you…

We hope this guide has provided you with some useful advice and the tools you need to go ahead with your own campaign for FES. We would love to hear from you about your successes as well as your trials and tribulations and we are here to help if you need any further advice about your campaign. Please email us on campaigns@mssociety.org.uk or phone the Policy and Campaigns team at the MS National Centre on 020 8438 0700.

And don't forget these helpful tips from our FES campaigners:

- ✔ **Do your homework – reading this guide will give you a good start in finding out everything you need to know about FES.**
- ✔ **Keep a positive attitude with the people you are dealing with – it's important to keep people on your side.**
- ✔ **Seek support from others.**
- ✔ **Keep records of names, dates and telephone numbers and keep all your paperwork in one place.**
- ✔ **Don't be afraid to copy and paste information from this guide to use in your campaign.**
- ✔ **Don't give up!**

You can keep up to date and informed about the campaigns that are going on around the UK by joining the MS Society Campaigns Network. Joining the network gives you the opportunity to report issues you may be facing in your area, influence national campaigns and gain more knowledge to assist you in your own local campaigning efforts. You can read more about the Campaigns Network here on the MS Society website - http://www.mssociety.org.uk/campaignsnetwork

Links to further information

Bioness
Manufacturer of FES equipment.
www.bioness.com/United_Kingdom.php

enAble
National UK event focusing on helping people with disabilities or limited mobility to lead an active, independent and full life.
www.enableshow.co.uk/

Independent Complaints Advocacy Service
The Independent Complaints Advocacy Service (ICAS) supports patients and their carers wishing to pursue a complaint about their NHS treatment or care.
Further information -
www.carersfederation.co.uk/what-we-do/icas/index.ph
Location of offices -
www.carersfederation.co.uk/what-we-do/icas/offices.php

MS Society
Campaigns news on FES –
www.mssociety.org.uk/fes
Information about a research project assessing the benefit of FES for people with MS, recently funded by the MS Society -
www.mssociety.org.uk/research/research_we_fund/grant_873.html
The MS Society's service development team can be contacted by emailing:
servicedevelopment@mssociety.org.uk

National Clinical FES Centre
Research website for Odstock Medical Ltd -
www.salisburyfes.com/
Please note, all enquiries should be sent to **enquiries@salisburyfes.com** or 01722 429065.

National Institute for Health and Clinical Excellence (NICE)
Interventional procedures guidance on functional electrical stimulation for drop foot of central neurological origin -
www.nice.org.uk/guidance/IPG278
Clinical guidelines on the management of multiple sclerosis in primary and secondary care -
www.nice.org.uk/CG8

Odstock Medical Limited
Manufacturer of clinical FES systems, based at Salisbury District Hospital.
www.odstockmedical.com/

PhysioFunction
Offers comprehensive private neurological physiotherapy for the treatment of neurological conditions. PhysioFunction provides services through the East Midlands, West and North Yorkshire and at the Oxford Centre for Enablement.
www.physiofunction.com/

Walkaide
Manufacturer of FES equipment.
www.walkaide.com

Appendix

Evidence that functional electrical stimulation is beneficial to people with MS who experience dropped foot

Burridge J, Taylor P, Hagan S, Swain I
Experience of clinical use of the Odstock dropped foot stimulator
Artif Organs. 1997 Mar; 21(3):254-60

Paper summary
This is a follow up of 56 patients using an FES stimulation device called an Odstock Dropped Foot Stimulator (ODFS). Five of these patients had MS, 50 had hemiplegia and 1 had spinal cord injury. When patients used the ODFS device for between six and 18 months they had a 14 per cent increase in walking speed at three months (compared to what they experienced before using the ODFS) as well as decreased effort of walking and improvement in functional mobility tests. Some people who used the device all day every day had some skin irritation and two participants discontinued use of the device because of increased spasticity in the calf.

Conclusion
The ODFS device increased walking speed over time and decreased effort of walking in people with dropped foot (including people with MS).

Taylor P, Burridge J, Dunkerley A, Wood D, Norton J, Singleton C, Swain I
Clinical audit of 5 years provision of the Odstock dropped foot stimulator
Artif Organs. 1999 May;23(5):440-2

Paper summary
This paper looked at the effects of the ODFS on walking speed, effort of walking and patients perspectives by questionnaire. They found that after 4.5 months of using the ODFS, 111 stroke patients showed an average increase in walking speed of 27 per cent and a reduction in walking effort of 31 per cent. The 21 people with multiple sclerosis who used the device achieved similar improvements.

Conclusion
The ODFS device increased walking speed and reduced walking effort over a period of 4.5 months in 21 people with MS who had dropped foot.

Taylor PN, Burridge JH, Dunkerley AL, Lamb A, Wood DE, Norton JA, Swain ID
Patients' perceptions of the Odstock Dropped Foot Stimulator (ODFS)
Clin Rehabil. 1999 Oct;13(5):439-46

Paper summary
This paper looked at patient-reported outcomes and perceived benefit of the ODFS device as well as the users' opinion of the service provided. A survey was sent to 168 current and 123 past users (people with stroke, multiple sclerosis, spinal cord injury and cerebral palsy) of the ODFS device. The main reason for using the device was that the ODFS decreased walking effort. The main reasons for discontinuing the device were an improvement in mobility, difficulties with using the device and deteriorating mobility. Overall the ODFS was perceived to be of benefit.

Conclusion
The ODFS device appears to be perceived as useful by people with dropped foot (including people with MS).

Paul L, Rafferty D, Young S, Miller L, Mattison P, McFadyen A
The effect of functional electrical stimulation on the physiological cost of gait in people with multiple sclerosis
Multiple Sclerosis 2008;14:954-61

Paper Summary
This was a controlled clinical study to determine the effects of FES on walking speed and effort in people with MS. In this study 12 people with MS and 12 people without MS (controls) walked at their own speed for 5 minutes with and without using FES. Control participants were matched with a person with MS and walked at the same speed. People with MS displayed an improvement in walking speed and a reduction in walking effort when they were using FES. Walking effort in people with MS who used a FES did not match the controls.

Conclusion
FES offers improvements in walking speed and reductions in walking effort to people with MS.

Barrett CL, Mann GE, Taylor PN, Strike P
A randomized trial to investigate the effects of functional electrical stimulation and therapeutic exercise on walking performance for people with multiple sclerosis
Multiple Sclerosis 2009;15:493-504

Paper Summary
This was a randomised controlled trial to assess the effects of FES compared with therapeutic exercise in people with secondary progressive MS who experienced dropped foot. In this trial, 20 participants received FES and 24 participants received a physiotherapy home exercise program for a period of 18 weeks. All participants did a 10 metre timed walk, tests to measure effort of walking and a measurement of the distance walked in three minutes. Additionally, participants in the FES group underwent testing both with and without FES stimulation. Walking speed, walking effort and average distance walked were all significantly improved in people who were walking with FES stimulation (compared with when they were walking without stimulation). Walking speed and average distance walked improved in participants receiving therapeutic exercise and overall, more improvements were seen in the group receiving therapeutic exercise than those receiving FES.

Conclusion
Therapeutic exercise in combination with FES may be more beneficial in people with MS than either treatment alone.

Stein RB, Everaert DG, Thompson AK, Chong SL, Whittaker M, Robertson J, Kuether G
Long-Term therapeutic and orthotic effects of a foot drop stimulator on walking performance in progressive and non-progressive Neurological disorders.
Neurorehabil Neural Repair. 2009 Oct 21. [Epub Ahead of Print]

Paper summary
This paper looked at the orthotic and therapeutic effects of functional electrical stimulation in 41 people with non-progressive stroke and 32 people with progressive multiple sclerosis (MS) for three to 12 months. Walking speed was measured using a 10 metre timed walk and a four-minute figure eight test. Orthotic effect of the FES system was measured by testing walking speed whilst the device was on and off and therapeutic benefit was measured by comparing walking speed and effort before and after use of the FES system. After 11 months the combined therapeutic plus orthotic effect on figure-8 speed showed a 13.1 per cent improvement in people with MS. There was also a 6.5 per cent decrease in walking effort.

Conclusion
Patients with progressive MS have orthotic benefit from FES up to 11 months.

A review of evidence in stroke
Kottink AI, Oostendorp LJ, Buurke JH, Nene AV, Hermens HJ, IJzerman MJ
The orthotic effect of functional electricl stimulation on the improvement of walking in stroke patients with a dropped foot: a systematic review
Artif Organs. 2004 June;28(6):577-86

Paper summary
This is a systematic review of eight studies looking at the effects of functional electrical stimulation in stroke patients with dropped foot. One of the studies was a randomised controlled trial. Two independent raters scored the quality of the eight studies and looked at the effect of functional electrical stimulation on walking speed and effort. The review found a pooled improvement in walking speed by 38 per cent.

Conclusion
This review suggests a positive effect of functional electrical stimulation on walking speed of patients with dropped foot.

Acknowledgements

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