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1. Introduction

This booklet has been written by the Spasticity Team at The National Hospital for Neurology and Neurosurgery.

It is intended for patients (or their family or carers) who have been referred to our service or are under the care of the team at this hospital. It is not intended to replace discussion with your consultant.

If you have any questions about spasticity please do not hesitate to contact a member of our team, we will be happy to answer them for you.

2. What does spasticity mean?

Spasticity can be described as involuntary muscle stiffness. It can range from mild to severe and change over time, often from day to day or hour to hour. Symptoms can be unpleasant but sometimes spasticity can be helpful; if a person’s legs are very weak the stiffness spasticity causes may actually help in transferring from bed to chair or even in walking.

The key to successful management of spasticity is the individual, who needs to be aware of management strategies they can incorporate into daily life.

3. How does Spasticity occur?

Nerve pathways connecting the brain, spinal cord and muscles work together to co-ordinate movements of the body.
These pathways can be disrupted in neurological conditions such as stroke, multiple sclerosis, head or spinal cord injury, leading to loss of this co-ordination and over activity of muscles causing spasticity.

4 What are the symptoms?

The main feature of spasticity is stiffness or increased resistance when attempting to move a limb or joint. Other features that may be associated with it include spasms, pain, weakness and clonus.

Stiffness or increased resistance to movement

Some people with spasticity describe that their muscles feel stiff, heavy and are difficult to move. When very severe it can be very difficult to bend a limb at all.

Your health care team may comment on the tone in your limbs. Muscle tone is described as the resistance felt when trying to move or stretch an arm or leg. Normal tone is when an individual is relaxed and can bend and straighten the limb without difficulty. When spasticity is present there is an increased resistance to movement (an increase in tone).

Muscle stiffness and increased tone can also occur in an individual’s trunk/body. Sometimes individuals can have mixed symptoms. For example their trunk/body may be weak/floppy but their legs may be stiff and difficult to move. These mixed symptoms need careful management.
**Spasms**

Spasms can be described as sudden involuntary contractions of muscles that can make your arms, legs or body move in different ways, for example:

<table>
<thead>
<tr>
<th>Flexor Spasms:</th>
<th>The limb will bend upwards towards your body</th>
</tr>
</thead>
<tbody>
<tr>
<td>Extensor Spasms:</td>
<td>The limb will shoot out away from your body</td>
</tr>
<tr>
<td>Adductor Spasms:</td>
<td>The limb will pull inwards towards your body. Commonly this can be when your thighs stay together and it is difficult to separate them</td>
</tr>
</tbody>
</table>
Severe spasms may make your back arch off the bed or chair.

**Pain**

Spasticity can be painful, but not always. If pain is present it may be linked to spasms, stiff muscles or is a consequence of altered sitting and lying positions.

**Weakness**

Despite a limb resisting movement (an increase in tone) the muscles may also be weak; this may increase the feeling of heaviness in arms or legs.

**Clonus**

This is a repetitive, up and down movement, often of the feet; it may be observed as a constant tapping of a foot on wheelchair foot-plates.

Other symptoms associated with spasticity can include fatigue and loss of dexterity.
5. What problems can spasticity cause?

Spasticity and its associated features can affect all aspects of daily life. For example, it can affect the way you walk, transfer, sit in a chair, turn over in bed, carry out your care needs, sexual activities and it can affect your overall comfort and mood.

Furthermore, persistent spasticity can lead to poor postures in lying and sitting which can lead to pain, pressure sores or contractures (when a limb becomes fixed in one position). However there are many steps you can take to minimise the impact of spasticity on your daily life.

What can I do and who can help me?

Increasing your knowledge about spasticity, its associated features and what affects them can help you to manage it more effectively and prevent symptoms. Whether you have mild or severe symptoms medical, physiotherapy, nursing and occupational therapy treatment, advice and education could help increase your understanding and management. The following factors are particularly important as they can aggravate spasticity and its associated features.
<table>
<thead>
<tr>
<th>Aggravating Factors</th>
<th>Who can give management advice?</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Urinary retention or infection</td>
<td>Sometimes you may notice that your spasticity is becoming harder to manage; it may be that a review of your bladder, bowel and skin care management techniques will improve the situation. Advice and assistance to effectively manage your bladder, bowels and skin can be given by your GP, a nurse specialist, Continence Advisor or District Nurse.</td>
</tr>
<tr>
<td>• Bowel impaction, constipation, infection</td>
<td></td>
</tr>
<tr>
<td>• Red or broken skin, pressure areas</td>
<td></td>
</tr>
<tr>
<td>• Ingrown toenails</td>
<td></td>
</tr>
<tr>
<td>• Pain</td>
<td>Pain and infection will aggravate spasticity. If the source of the pain or infection can be located, for example a skin infection or an ingrown toenail, then treating this may help reduce your spasticity. Advice can be sought from your GP or District Nurse.</td>
</tr>
<tr>
<td>• Infections</td>
<td></td>
</tr>
<tr>
<td>• Poor positioning when sitting, lying and standing</td>
<td>A good position when lying, sitting or standing will help you manage your spasms, spasticity and prevent discomfort and contractures from developing. For example, when in any</td>
</tr>
</tbody>
</table>


If possible sit with your hips and bottom at the back of the seat with your knees and feet at right angles. Moving or putting weight through a limb that is in spasm can reduce its intensity, if you can do so safely either stand or lean forward in your chair to transfer weight to reduce lower limb spasms.

A physiotherapist or occupational therapist (or both) can advise on sitting, lying, standing posture and possibly suggest exercises to help manage your spasticity. If necessary your local wheelchair service can recommend a suitable wheelchair to optimise your management.

| Tight fitting clothes or splints | Simply loosening tight garments may help to relieve spasticity. If splints are causing discomfort or skin irritation then they will need reviewing by your orthotic or therapy services. |
6 What are the available treatments?

Physiotherapy

It is important to keep muscles, ligaments and joints as flexible as possible. Spasticity, spasms and weakness can result in muscle shortening and joint stiffness, which can in turn aggravate the spasticity and spasms. A physiotherapist can advise on how to maintain flexibility, teach specific stretches and advise on different ways of moving and positioning the body.

As well as looking at the above measures to reduce spasticity sometimes it is necessary to use medication to optimise management.

Oral Medication

Baclofen: This is the commonest medication prescribed for spasticity; it acts directly on nerve cells mainly in the spinal cord to decrease the excitability of the nerves and therefore reduces excessive muscle activity including spasms.

Most people do not experience side effects provided it is started at low doses (often at 5-10mg once or twice a day) and slowly increased, stopping at a dose that helps but does not cause any problems (maximum dose 40mg three times a day).

The effect of an oral baclofen dose can last between four to six hours so it needs to be taken regularly to ensure adequate control of symptoms.
Side effects can include weakness, drowsiness and dizziness. Baclofen should not be greatly reduced or stopped suddenly without asking your doctor as this can also cause side effects.

**Tizanidine**: This also works on the central nervous system and needs to be introduced slowly to avoid side effects (started at 2mg a day and increased up to a maximum of 36mg daily). It is claimed that it does not increase muscle weakness as much as Baclofen but this varies between individuals. When on this drug your doctor will regularly take blood samples to ensure it is not having any adverse effect on your liver function. Other side effects can include drowsiness, low blood pressure on standing and dry mouth.

**Diazepam and Clonazepam**: These drugs can be used alone or more commonly in combination with other drugs. Clonazepam is particularly useful taken at bedtime if spasms are a problem at night. The main side effect is drowsiness, which is not a problem if either drug is taken at bedtime. Neither diazepam nor clonazepam should be stopped suddenly without asking your doctor.

**Dantrolene**: This is the only antispasmodic drug that works directly on the muscles and not on the central nervous system. It can be used in combination with other drugs. Side effects are unfortunately quite common and include nausea, vomiting, diarrhoea and weakness.
Rarely dantrolene can cause liver problems therefore whilst on this drug your doctor will regularly take blood samples to check this is not a problem for you.

**Gabapentin and Pregabalin:** These drugs are used to treat epilepsy and some types of pain. It also has some effect on spasticity and can be used in combination with other drugs; it is particularly useful if pain and spasticity coexist. Gabapentin is started at a low dose (300mg per day) and increased up to a maximum of 1200mg three times a day. It should not be stopped suddenly without discussing with your doctor. Side effects include drowsiness, dizziness and blurred vision.

**Key Points in all drug treatments**

Using drugs to assist you in managing your spasticity can be invaluable. To get maximum benefit from your drugs work out the best time to take them that will help you carry out your activities during the day. For instance if getting out of bed is difficult, have your drugs next to your bed, take them when you wake up and wait 10 - 20 minutes before getting up.
What alternatives are available?

If your management strategies, therapy input and oral drugs are not providing adequate relief than the following treatments may be considered.

**Intramuscular Botulinum Toxin**: This is a toxin which when injected into muscles causes them to become weak and less stiff. It can take 14 days for the full effect to occur. It is useful for small muscles, and must be used in conjunction with physiotherapy/ occupational therapy.

Often the injections can allow the therapists to work with the muscle more effectively, to minimise the effects of the spasticity. Sometimes repeated injections are necessary.

**Intrathecal Baclofen**: When baclofen is taken in tablet form it first has to build up in the bloodstream before it can reach the nerve cells in the spinal cord or brain. Sometimes people can not tolerate a high enough dose of oral baclofen to help their spasticity, as the level in the blood is too high and causes side effects. In order to get the baclofen directly to the spinal cord it can be delivered by an implantable pump; this is placed in the abdomen and a catheter delivers the baclofen into the intrathecal space (the space around the spinal cord within the spine). It uses much smaller amounts of baclofen to treat the spasticity, thus reducing any side effects.

Intrathecal baclofen is used to treat generalised lower limb spasticity; it requires commitment from individuals not only during the trial and implant phase but also for its ongoing maintenance of regular refills and replacements.
Intrathecal Phenol: Injecting phenol into the intrathecal space stops the nerves conducting and is very effective in reducing lower limb spasticity. Although it is a permanent procedure, repeat injections are occasionally necessary due to wearing off. Transient negative effects on the sensation in your legs, sexual function and bladder and bowel management may occur.

However if you already have effective management strategies in place (such as a suprapubic catheter or use suppositories regularly) the use of intrathecal phenol may not cause you any further negative effects.

Surgery: Occasionally your Neurologist may recommend orthopaedic or neurosurgical procedures although these are rarely necessary.

7 How should I prepare for clinic?

To prepare it would be really helpful if you could consider what the main problem is that your spasticity or spasms can cause you on a daily basis, and which drug treatments you have previously trialled.

Please bring a list of all the medications you are taking

A list of the names and addresses of health care professionals currently involved in your care would be very useful as it is probable that we will need to contact them.
8 Asking for your consent and what happens during the clinic?

The assessment will be carried out by a Multidisciplinary Team including a Neurologist, Physiotherapist and Spasticity Nurse Specialist. This combination of roles allows us to offer advice regarding a comprehensive management plan. With your consent your limbs may be moved during the assessment but this will not mean you will need to change or remove any clothing.

During the consultation treatments to manage spasticity will be discussed and recommendations made. We will explain all the risks, benefits and alternatives of any treatments recommended and provide you with our contact details.

9. What should I expect after my appointment?

You will receive a details letter about the management plan following the assessment.

Depending on the recommendation we may complete a follow up call, get you back for an assessment in outpatients or organise an admission. If you have any queries you can contact the team to discuss.
10. Where can I get more information and support?

MS Society National Helpline  ☏ 0808 800 8000  
www.mssociety.org.uk

MS Research Trust  ☏ 01462 476700  
www.mstrust.org.uk

The Neurological Alliance  ☏ 0207 463 2074  
www.neural.org.uk

Medtronic  
www.medtronic.com

British Brain and Spine Foundation Helpline  ☏ 0800 808 1000  
www.brainandspine.org

The Continence Foundation Helpline  ☏ 0845 345 0165  
www.continence-foundation.org.uk

UCLH cannot accept responsibility for information provided by external organisations.
11. **Contact details**

Spasticity Service
The National Hospital for Neurology and Neurosurgery
Box 113
Queen Square
London
WC1N 3BG

Spasticity nurses: 020 3448 3439
Spasticity physiotherapists: 020 3448 3170
Switchboard: 0845 155 5000 / 020 3456 7890
Fax: 020 3448 3711
Website: www.uclh.nhs.uk/nhnn

https://www.uclh.nhs.uk/OurServices/ServiceA-Z/Neuro/SPAS/Pages/Home.aspx
12 How to find us

Give details of how to find the relevant clinic/ward/dept here
Space for notes and questions