

LIVING WITH SCI

FACTSHEETS

sia spinal
injuries
association
FOR LIFE AFTER SPINAL CORD INJURY



PAIN MANAGEMENT

Introduction

In most cases pain is your body's warning system that alerts you when something is wrong. It is an unpleasant sensory and emotional experience that warns of actual or impending injury or illness. Pain following spinal cord injury is a major and common problem that has been reported as the most important factor for decreased quality of life in spinal cord injured (SCI) people.

It is estimated that up to 82 percent of SCI people are affected by chronic pain. Although a lot of research is being carried out in this field, the focus of many pain consultants and other health professionals is on pain management, rather than a cure.

Severe pain can compromise your rehabilitation as a SCI person and can have significant impact on other aspects of your life such as returning to employment, day to day social interaction and even how well you sleep. Some SCI people who suffer from chronic pain can find that it is the severity of the pain that is disabling rather than the paralysis caused by SCI.

“Pain is a very subjective thing; no-one else can know what you are feeling. There is only one good definition of pain: Pain is what you say hurts” Anon

“My pain makes me totally exhausted - I've had to change my habits to allow for this. I don't go out socially on work days and measure out my social life accordingly. People just have to come and see me sometimes, rather than me doing the visiting... Friends forget about your pain because it's not visible, and expect you to keep up/join in. I find you have to be firm and not allow yourself to be cajoled or bullied into things.” SCI woman, L1/2 incomplete

What are the different types of pain that accompany SCI?

There are different types of pain that can accompany SCI and it is notoriously difficult to categorize them due to the wide disparity in location, type, duration and severity of the pain.

How long pain lasts varies from person to person. You might suffer a period of acute pain soon after your injury, or you may have episodes of pain at different times over the years following injury. Alternatively you may have chronic pain, which is a regular, often debilitating phenomenon. If you have an incomplete lesion, you may experience hypersensitivity of certain areas of the skin or specific limbs, making your body extremely sensitive to touch and which can feel just like pain.

It had been quite problematic for the medical professionals to agree on pain terminology and grading because they were uncertain about how the pain came to be. The International Association for Study of Pain then proposed a standard classification of SCI pain

Under this classification, there are two main types of SCI pain: nociceptive and neuropathic.

Nociceptive Pain

In nociceptive pain, special nerve fibres, known as nociceptors, sense irritation, impending injury or actual injury to your body. Nociceptors are found primarily in the skin, joints and walls of organs. They send pain signals via peripheral nerves and spinal cord to the brain, making you conscious of the pain.

Nociceptive pain is described as a dull, throbbing pain that is confined to one specific area, and once the site of injury heals, the pain usually disappears shortly after. The cause of this type of pain can be either from the musculoskeletal system (bone fracture, rotator cuff tear) or visceral system (ulcers, appendicitis). The musculoskeletal system consists of muscles and skeleton, and gives your body the ability to move. Your heart, liver, intestine and other internal organs make up the visceral system.

Pain due to musculoskeletal system

This type of pain occurs above or at the level of SCI and is a result of damage to tendons, bones or joints. Moving the injured body part worsens the pain and treatment frequently includes rest.

Secondary overuse is a common cause of musculoskeletal pain and is caused by wear and tear of the shoulder, wrist and elbow joints. Doing multiple transfers, pushing a manual wheelchair and other repetitive daily activities you engage in as a SCI person put excessive stress and strain on your joints.

Over months or many years of your joints bearing the brunt of such activities, you may develop shoulder pain, bicep tendonitis, carpal tunnel syndrome or rotator cuff tears.

- *Rotator cuff tear* is damage to the tendon and surrounding soft tissue and can be partial or complete. When too much pressure is put on the tendons, their blood circulation is decreased and a tear may occur. The most common symptom is pain and/or weakness when attempting to reach above your head with your hand.
- *Bicep tendonitis* is inflammation of your bicep tendon and is caused by fraying of the tendon. Symptoms usually are a pain near the middle of your shoulder especially if you try to reach behind your back. It would not be advisable to shrug off this pain because you may lose some of your active shoulder movements if you do not seek treatment.

- *Carpal tunnel syndrome* is a painful condition that occurs when the median nerve, running from your forearm into your hand, is compressed through a narrow tunnel in your wrist. It is caused by excessive hand use through activities. The symptoms start gradually and are usually pain or tingling in your thumb, index and middle fingers.

Treatment of pain due to secondary overuse is fairly straightforward. By modifying activities that put stress on your joints, you can manage secondary overuse pain effectively. You could stop or limit activities that worsen the pain; for example, it may help to limit pushing a manual wheelchair if you have shoulder pain. Alternatively you may opt to switch from a manual to a power wheelchair. Non-steroidal anti-inflammatory medications, hydrotherapy and changes in posture and physiotherapy are some therapies that may be used.

Pain due to visceral system

Visceral pain affects the abdominal region and can be caused by gastrointestinal complications such as ulcers, constipation or appendicitis. However there have been cases where it can manifest itself as neuropathic pain when there is no medical problem. Treating this pain involves paying attention to the presumed source of pain for example changes in diet may relieve constipation.

Neuropathic pain

“...alternates between intense heat and cold-strangling, stabbing pain, like a knife turning. It’s very debilitating”
SCI person, T10/12

Neuropathic pain or nerve pain puzzles and frustrates both SCI people and their doctors because of the mysterious nature of its cause. In neuropathic pain, your nervous system generates and perpetuates this pain without any ongoing stimuli from injury. It is generally believed that the pain arises from damage to the nerve endings at the site of SCI. A paradox of SCI is that while it deprives you of normal sensation and movement in part of your body, you may still experience pain in areas that otherwise have no sensation. This pain can be severe and debilitating. Most people describe neuropathic pain in the following terms:

- Burning
- Searing or scalding
- Cold
- Numb
- Tingling
- Shooting

- Stabbing
- Vice-like.

Neuropathic pain is classified according to where you feel it:

Above-level neuropathic pain

Segmental deafferentiation – occurs around the border where you still have normal sensation and loss of sensation as a result of SCI. It can be experienced slightly above SCI or slightly below, usually during the first few months post-injury or may develop slowly over time.

If you have a cervical SCI, you may describe segmental pain as a burning, numbing pain that spreads over your shoulders, arms and hands. If you have a thoracic SCI, you may say it is vice-like and feel tightness and pain around the chest and abdomen.

If your injury is in the lumbar region, the pain may be in groin area and lower extremities.

Another complication of this type of pain is *allodynia*, where things that do not normally cause pain begin to such as cold/warmth, or very light touch to skin by clothing. You may also get *hyperalgesia*, where what would cause mild pain, like a pin-prick, feels extremely painful.

“A vice being tightened around my waist with all the organs below this being squeezed. It feels like everything is hurting and disintegrating and is exacerbated by constipation, ovulation and periods. It got so bad that the doctors stopped my periods with hormonal treatment. I also get incredible pain in and around both knees as though someone had ‘knee-capped’ me.”

SCI Woman, L1/2 incomplete

At-level neuropathic pain

Nerve root entrapment – caused by compression of a nerve root by bone or spinal disk. It has a distinct pattern and you may find that the pain feels like brief waves of stabbing or sharp pain or a band of burning pain at the point where normal sensation stops.

If you have cauda equina, you may feel a burning feeling in your lower extremities including pelvis, genitals and rectum.

Syringomyelia – is rare amongst SCI people and affects the centre of the spinal cord, adjacent to the damaged area. A fluid-filled cavity (syrinx) forms and enlarges like a tube. It puts pressure on the spinal cord as it grows upwards and downwards from the site of injury.

The primary symptom of syringomyelia is burning/stabbing pain and is nearly always on one side of the upper body. This may be accompanied

by numbness or erratic sensations spreading upwards from your SCI and you may sweat more, have muscle weakness and be less sensitive to hot and cold temperatures.

Below-level neuropathic pain

This is also known as central pain and often begins weeks or months after your injury. You may experience a pins and needles feeling, numbness or a burning feeling throughout the area below your level of injury. Some people describe central pain as simply bothersome while other say it can be debilitating and so it varies from individual to individual.

“The pain is in my legs, mainly below the knees to my ankle. It’s strange, searing pain, rather like having red hot barbed wire moving about in my limb. It also throbs”

SCI person, C3 incomplete

“...I feel the pain from my toes to chest level. Incredibly difficult to describe- unlike anything known as pain before the accident. Tightening of toes and feels as if my toes and heels are contracting in towards each other (I used to call this ‘Chinese feet’). I have a constant, mild to intense burning sensation in my legs and from my stomach to chest, an overall tightening of muscles which can produce backache”

SCI person, C6/7 incomplete

Radicular pain

You may experience this type of pain at any level. It is caused by damage to the nerve root by bony fragments, bulging disc material or inflammation. Frequently affecting one side of the body; it is described as shooting, burning, aching or crushing. The first onset is within days to weeks after your injury.

How is neuropathic pain treated?

Neuropathic pain has been known to be notoriously unresponsive to conventional pain therapies. Even being diagnosed as having neuropathic pain has been an uphill task for some people. The reality of pain for some people is that their life and ability to live it successfully is seriously compromised.

This is mainly because the sites where the pain is present have not only been clinically classified as numb, but some medical professionals are sceptical of pain if they cannot directly observe its physical cause or prescribe an effective remedy.

Psychological factors such as feeling depressed or upbeat can aggravate or relieve the pain symptoms respectively. This only reinforces the scepticism that some doctors have. However, these psychological factors do not mean that you are imagining the pain, but rather that you may be able to bring some relief through cognitive behavioural therapy. This type of therapy is based on the principle that certain thinking patterns can trigger health problems and, by identifying and changing these unhelpful thoughts, you gain control over your pain.

Managing your pain may include a variety of treatments since no 'pain' is the same and different people react differently to pain relief therapies and no one method suits everyone. Sometimes you may find that a treatment works at first then loses its effectiveness over time. More often than not, your treatment will require a combination of different therapies.

You may find that you will have a multi-disciplinary team at a specialised pain clinic, advising you on pain management and this may include a pain consultant, a neurologist, social worker, occupational therapist, physiotherapist and a psychologist/psychiatrist. You may ask your GP to refer you to a pain clinic or contact the British Pain Society (**See Useful Organisations**), who can help you find one near to you that your GP may then refer you to.

The pain clinics will work with you to manage your pain more effectively. Some individuals have found that having medical professionals who are prepared to listen to them and believe their experiences with pain offer an enormous psychological boost. You will be given a thorough assessment which will include a detailed pain history to better understand the outcomes of previous treatments, what aggravates/relieves your pain, general quality of life and available social support.

The pain clinics usually take a holistic approach, so that as well as using conventional medicine by assessing your drug regimen, they also look at alternative therapies and relaxation techniques.

Pharmacological therapies

The majority of analgesics and non-steroidal anti-inflammatory drugs (NSAID's) have little effect on pain caused by nerve pain (damage). Your GP may prescribe a drug that is not licensed to treat neuropathic pain and was rather developed to treat medical conditions such as epilepsy or depression. These drugs are prescribed 'off- license' because there is research-based evidence of their effectiveness on relieving neuropathic pain, and so you should not let this alarm you.

i) First line of treatment

Following your assessment by your GP or pain consultant, you may be prescribed gabapentin and/or a moderate opiate such as tramadol as a first line of treatment. Gabapentin is part of a drug family known as anti-convulsants which are primarily used to control

epilepsy and also to treat chronic pain. The drugs act by calming the over-excitabile nerves.

Gabapentin has increasingly become a first choice for pain specialists because it is effective in relieving pain, and has low incidence of side effects.

Pregabalin is a newer drug that has been developed to specifically treat neuropathic pain. Sedation, dry mouth, nausea, vomiting, dizziness and skin rashes are the common side-effects you may experience when taking anti-convulsants. You reduce the risk of developing these side-effects if you build up the dose gradually.

Tramadol is part of the opioids family that includes morphine and methadone, and since they are not specifically directed to neuropathic pain, it may or may not work on some people.

Constipation, nausea, sedation, vomiting, sweating and itching are some common side-effects reported from using opioids.

ii) Second line of treatment

If the first line of treatment is not effective then you may be prescribed intravenous lignocaine (also known as lidocaine) infusion, which is injected into a vein. This anaesthetic drug works by blocking sodium channels, which are believed to trigger nerve impulses that result in pain. Tricyclic antidepressants such as amitriptyline and nortriptyline are another family of drugs that are prescribed as second-line of treatment for neuropathic pain. They work directly on the brain and spinal cord, but are usually used in conjunction with an anticonvulsant or opioid as research shows they are not as effective when administered on their own. Common side effects of tricyclic antidepressants include drowsiness, dry mouth, blurred vision, constipation, and urinary retention.

iii) Third line of treatment

A strong opiate is the next line of treatment such as morphine, alfentanil and propofol which are administered intravenously and so can only provide short-term pain relief. Anxiety, nausea, vomiting and low blood pressure (hypotension) are some of the side effects that have been reported. Your doctor will carry out a risk assessment prior to prescribing an opiate to reduce risk of you becoming dependent on the drug.

Your doctor might consider surgical intervention where the drugs such as intrathecal morphine, clonidine, or intrathecal baclofen (particularly effective for spasm-related pain) are administered directly to the spinal cord via an implanted pump. These may be used on their own or as a combined therapy. Some people have reported increase in pain, drowsiness and low blood pressure after being on these treatments.

i) Fourth line of treatment

When all palliative treatments fail, more invasive surgical interventions may be tried as a last resort but there is little or no evidence for their effectiveness. Some people have found that surgery may even exacerbate the pain. Dorsal Root Entry Zone (DREZ) lesioning and Spinal Cord Stimulation (SCS) are some procedures that have shown some improvements in neuropathic pain but the evidence is weak and for people with complete injuries, they have proven to be ineffective. As with any surgery, there are certain risks that should be considered. There is the possibility of having an adverse reaction to anaesthesia, and there may be infection or bleeding. In certain cases, your bladder, sexual and bowel functions may be altered.

Non-pharmacological therapies

Physiotherapy, occupational and complementary therapies fall under this umbrella, and their incorporation in the treatment plan is instrumental in successfully managing pain.

Complementary therapies are numerous and vary greatly. How beneficial they are differs from individual to individual and although not definite, there is emerging evidence to support their efficacy in pain management programmes.

SIA members have reported that various complementary therapies have provided pain relief including acupuncture, aromatherapy, hypnotherapy, reflexology, osteopathy, shiatsu and yoga.

Acupuncture, one of the most established and popular complementary therapy has long been used in pain clinics as part of the pain management programme.

If you decide to try complementary therapy, you should ensure that the practitioner is registered with a professional body such as British Complementary Medicine Association ([see Useful Organisations](#)), which guarantees that professional conduct and ethics is maintained.

Physiotherapy predominantly involves improving fitness, mobility and posture through manipulation techniques, therapeutic exercise, movement analysis and restoration of normal movement patterns.

Biofeedback has been beneficial in some cases. It involves using special machines to train you to control bodily functions that your body does automatically such as heart rate and muscle tension. As it is believed that relaxation is a key component in biofeedback treatment, you will learn how to relax and modify your behaviour during a pain attack to counteract its effects.

Therapeutic massage has provided pain relief for some people, and improved their general well-being. The Snoezelen at the Princess Royal Spinal Injuries Unit, a multi-sensory room equipped with a variety of lighting effects, peaceful music and a large 'bean' bag, is used to employ different therapeutic massage techniques that not only provides pain relief but improved emotional well-being from having soothing physical contact.

(For more information, contact the Sheffield Spinal Injuries Unit, (See Useful Organisations))

Coping strategies

Cognitive-behavioural therapy can help you manage chronic pain by changing your attitude, beliefs and behaviour in relation to your pain. You are encouraged to keep a pain journal where you can identify your pain levels such as when you have the most energy, what time of the day do you experience high levels of pain, etc. as well as pain-aggravating thoughts and activities. From this information, you can learn how to control these factors and essentially control your pain.

Some techniques used include pacing yourself, goal setting, dealing with flare-ups, anger management, relaxation and distraction techniques. The distraction technique is widely used by many SCI people to manage their pain, and relieve stress. It basically means taking your mind off the pain and turning your attention to something else, to induce positive mental thoughts. You can listen to music, watch television, or get absorbed in a favourite hobby that will keep you engrossed. Some people find relaxation techniques like breathing in a slow, rhythmic manner and/or repeating self-motivating mantras like 'I can overcome this', to be effective.

Chronic pain can have an understandably huge impact on your emotional health, which in turn worsens the pain. Changing your mood through alternative therapies will make the pain less noticeable and will help you cope with it more effectively. Do not become a recluse and avoid social activities. Get involved in sports and leisure activities that appeal to you and make you feel happier and relaxed. Having a positive attitude is the key to long-term management of pain and improving your quality of life. Ensure your loved ones and carers are well informed about your treatment plan, and are available to provide emotional and practical support as needed.

Appendix 1 - SCI Pain Classification

BROAD TYPE (Tier one)	BROAD SYSTEM (Tier two)	SPECIFIC STRUCTURES/PATHOLOGY (Tier three)
Nociceptive	Musculoskeletal Visceral	Bone, joint, muscle trauma or inflammation Mechanical instability Muscle spasm Secondary Overuse syndromes e.g. Renal calculus, bowel, sphincter dysfunction, etc

<p>Neuropathic</p>	<p>(above- level) (at-level) (below-level)</p>	<p>Compressive mononeuropathies Complex regional pain syndrome Nerve root compression(including cauda equina) Syringomelia Spinal corc trauma/ ischaemia (Endzone , borderzone, etc)</p>
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Siddall PJ, Middleton J W.A proposed algorithm for the management of pain following spinal cord injury. *Spinal Cord* (2006) **44**, 67–77.

Appendix 2 - Useful organisations

Action on Pain

PO Box 134

Shipdham

Norfolk IP25 7XA

T: 01760 725993

Painline: 0845 6031593 (Mon- Fri: 1000hrs-1600hrs, answer phone at other times)

@: aopisat@btinternet.com

W: www.action-on-pain.co.uk

A charity providing advice and support to people living with pain. Run almost entirely by volunteers, many of whom are living with pain. They also have regional self-help groups and a dedicated helpline, manned by people living with chronic pain and offering a listening ear and advice and produce publications on various pain therapies.

The British Complementary Medicine Association

P.O. Box 5122

Bournemouth BH8 0WG

T: 0845 345 5977

@: office@bcma.co.uk

W: www.bcma.co.uk

Leading UK umbrella body for complementary medicine and represents many therapies and promoting the best in complementary medicine.

British Register of Complementary Practitioners

Can Mezzanine

32-36 Loman Street

London SE1 0EH

T: 020 7922 7980

@: info@icnm.org.uk

W: www.icnm.org.uk

Professional register of practitioners who have proved their competence to practise by completing an approved course or through assessment made by the Registration Panel, agree to abide by a Code of Ethics and Practice and have full practitioner insurance. Provides a focus for people interested in all forms of complementary medicine, and keeps a register of practitioners, also listed on their web site. Send a S.A.E. and a note of information you require.

British Pain Society

Third Floor
Churchill House
35 Red Lion Square
London WC1R 4SG
T: 020 7269 7840
@: info@britishpainsociety.org
W: www.britishpainsociety.org

Professional body representing healthcare professionals involved in the management and understanding of pain in the United Kingdom. Promotes education, training, research and development in all fields of pain. Aims to increase professional and public awareness of the prevalence of pain and the facilities that are available for its management. Unable to provide individual medical advice but can supply general information and a list of Primary Care Trusts in England, who can provide information on local pain services.

DIPEX

PO Box 428
Witney OX28 9EU
@: info@dipex.org
W: www.dipex.org

Website for a range of health issues, including a section on chronic pain containing videos, audio and written accounts of people's pain experiences along with information about chronic pain and available treatments. Has an online forum where people can interact, share and seek opinions about pain experiences.

Institute for Complementary and Natural Medicine

Can Mezzanine
32-36 Loman Street
London SE1 OEH
T: 020 79227980
@: info@icnm.org.uk
W: www.icnm.org.uk

Can supply the name of practitioners of a variety of complementary medicine such as homeopathy, relaxation techniques and osteopathy. Holds the British Register of Complementary Practitioners, has contact with various support groups and can supply a list of courses on complementary medicine. Prefers contact in writing or via the website.

Multidisciplinary Association of Spinal Cord Injury Professionals (MASCIP)

@: linda.hall@buckshop.nhs.uk

W: www.mascip.co.uk

Enables professions and grades of staff associated with the care and welfare of people with spinal cord injuries, both within and outside of spinal cord injury centres, to articulate professional issues and concerns and produces a guideline for the identification and treatment of pain following SCI, which can be downloaded from their website.

The Neuropathy Trust

PO Box 26

Nantwich

Cheshire CW5 5FP

T: 01270 611 828

W: www.neuropathy-trust.org

National, patient-led, non-profit organization supporting people with peripheral neuropathy and neuropathic pain. Raises awareness of neuropathic disorders.

Pain Relief Foundation

Clinical Services Centre

University Hospital Aintree

Lower Lane

Liverpool L9 7AL

T: 0151 529 5820

@: secretary@painrelieffoundation.org.uk

W: www.painrelieffoundation.org.uk

Maintain a range of pain information leaflets; available from the website or by sending an A4, 50p SAE. A donation would also be appreciated to cover printing, postage and packing costs.

Pain Support

@: support@painsupport.co.uk

W: www.painsupport.co.uk

The Pain Support website provides information, advice, contact with others and support for those in pain. The information includes pain management skills for reducing and coping with pain, how to deal with flare-ups, and much more. Contact is provided through a confidential contact club and discussion forum. Many self-help books, CDs and downloads are available to buy on line. Regular helpful email newsletters, plus free pain relief "toolkit" and free pain logs.

Skip - Supporting Kids In Pain

School of Health Science
University of Wales Swansea
Singleton Park
Swansea SA2 8PP
T: 01792 703771
@: t.d.barton@swan.ac.uk
W: www.shsskip.swan.ac.uk

Support network for families with children who have Complex Regional Pain Syndrome (CRPS), a form of Reflex Sympathetic Dystrophy. The site provides information on neuropathic pain and its associated syndromes (CRPS, RSD, Causalgia) and on arterio venous malformations in children.

Talking Life

36 Birkenhead Road
Holylake
Wirral
Merseyside CH47 3BW
T: 0151 632 0662
@: wendy@talklife.u-net.com
W: www.talkinglife.co.uk

Produce tapes, CDs and books on subjects including depression, pain management, bereavement, self esteem and assertiveness, anxiety, sleep problems etc. Hold seminars on back pain, stress and depression aimed at professionals.

The Princess Royal Spinal Injuries Centre

Northern General Hospital
Herries Road
Sheffield S5 7AU
T: 0114 226 6981 (unit)
T: 0114 243 4343 (hospital)
W: www.sth.nhs.uk or (search for Northern General Hospital)

Wessex Rehabilitation Centre

Salisbury Healthcare NHS Trust
Salisbury District Hospital
Odstock
Salisbury
Wiltshire SP2 8BJ

Secretary: 01722 336262 Ext 2370

W: www.salisbury.nhs.uk

Specializes in the management, physical and psychological aspects of hand conditions, acute and chronic upper limb trauma, chronic spinal pain, complicated or multiple trauma, complex regional pain syndrome and burns. Personalized treatment regimes are built around one or more of these facilities on a full day 5 day a week basis according to need, with the opportunity for overnight hostel accommodation, and are usually for periods of up to four to six weeks. Teams include a consultant in rehabilitation medicine, senior nurse, OT's, physiotherapists and clinical psychologists.

Wolfson Neurorehabilitation Centre

Copse Hill
Wimbledon
London SW20 0NQ

Enquiries: 020 8266 6505

W: www.sghms.ac.uk

32-bed rehabilitation centre for patients with acquired neurological disability and chronic pain, administered by St George's Healthcare Trust. Post-acute, in-patient and out-patient rehabilitation care provided. Assessment and treatment service, clinical neuropsychology, occupational therapy, speech and language therapy, ophthalmology, pain clinic. A hydrotherapy pool is available.

Disclaimer

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ABOUT SIA



The Spinal Injuries Association (SIA) is the leading national user-led charity for spinal cord injured (SCI) people. Being user led, we are well placed to understand the everyday needs of living with spinal cord injury and are here to meet those needs by providing key services to share information and experiences, and to campaign for change ensuring each person can lead a full and active life. We are here to support you from the moment your spinal cord injury happens, and for the rest of your life.

For more information contact us via the following:

Spinal Injuries Association
SIA House
2 Trueman Place
Oldbrook
Milton Keynes
MK6 2HH

T: 01908 604 191 (Mon – Fri 9am – 5pm)

T: 0800 980 0501 (Freephone Advice Line, Mon – Fri, 11am – 1pm/2pm – 4.30pm)

W: www.spinal.co.uk

E: sia@spinal.co.uk

Charity No: 1054097

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