

LIVING WITH SCI

FACTSHEETS

sia spinal
injuries
association
FOR LIFE AFTER SPINAL CORD INJURY



FATIGUE

Introduction

Fatigue is a symptom rather than a condition, and is all too common with today's often hectic and demanding lifestyles. It affects people of all ages, at any stage of life and is associated with a lack of energy and motivation. Healthcare professionals can find it difficult to distinguish fatigue from other common symptoms such as tiredness, which may lead to a situation where the problem is not treated until it has become chronic.

Fatigue in spinal cord injury (SCI) is under-reported, under-researched and not sufficiently understood. It tends to affect females more than it does males, with the level of injury appearing to be relevant as well, as people living with tetraplegia report more fatigue than those living with paraplegia: these are the findings of a longitudinal study of 300 British SCI cases who had been living with their injury for more than 23 years.

This fact sheet presents some actions and techniques you may wish to consider to help reduce your level of fatigue and stop the problem getting out of control. You should not have to put up with chronic fatigue.



Take fatigue seriously – it may be associated with how long you have been injured, and is unlikely to go away on its own.

What causes fatigue?

Fatigue can be caused by a combination of factors, and listed below are some of the most common causes.

Medical conditions:

- Anaemia
- Respiratory problems
- Diabetes
- Metabolic disorders e.g. thyroid deficiency
- Immune system disorders
- Pain – chronic / severe
- Infections – bacterial or viral e.g. urinary tract and respiratory tract
- High levels of spasticity
- Low blood pressure (hypotension)
- Depression and other psychological conditions
- Frequent episodes of autonomic dysreflexia

Medications:

- Certain painkillers and muscle relaxants (check with your GP)

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Other causes:

- Alcohol and drug abuse
- Performing daily tasks
- Transferring many times during the day
- Pain
- Mood swings / anxiety / boredom
- Stress
- Chronic headaches
- Obesity and lack of exercise
- Unhealthy eating and not drinking enough water
- Sleep disturbances e.g. waking up to perform bladder management or pressure relief.

The effects of fatigue

Over time our muscle mass reduces and leads to an increased weakness, which in turn affects muscle function. As a result you can find yourself lacking the strength to perform regular routines properly and avoiding certain tasks, which could be a risk to your health and general wellbeing e.g. if you don't have the strength to transfer properly, you risk shearing injuries which can lead to pressure ulcers.

You may risk ill health if you don't eat healthily because you feel too tired to prepare proper meals, and those with an incomplete injury who are able to walk are just as likely to experience fatigue as those with complete injuries since walking with crutches or sticks over many years can also lead to fatigue.



Chronic Fatigue can result in:

- Memory problems
- Impaired concentration
- Sleep disturbances
- Weakness / dizziness
- Depression, relationship issues and isolation

Tips and action to consider

Keeping a diary can be useful for reporting symptoms to your GP and Spinal Consultant, and for your own benefit to monitor progress. You may wish to record the following:

- How severe you feel your fatigue is; devise a scoring system using a scale of 1-10
- Feelings of weakness; is it worse in the morning or evening?
- Is your fatigue related to physical activity?

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- Is your fatigue related to your mood?
- What makes your fatigue better?

Make small changes to your daily routine using evidence from your diary. If you can identify what makes you tired and at what time of the day it occurs, then you can start to make some adjustments.

- Try to determine the underlying cause of your increased weakness, is it perceived or actual?
- It is important to pace yourself, as in getting the balance right for you between exercise, activity and rest
- Exercise of the right type and quantity e.g. yoga, Pilates; it is a good idea to have a physiotherapist help you devise which type of exercise is best for you
- Eating good quality nutritious food and taking enough fluids will help your general feeling of wellbeing. Try to eat smaller meals more regularly, instead of large meals which take a lot of energy to digest
- Experiment with relaxation techniques such as mindfulness. For some people, just 10 minutes a day can help them to re-energise.
- Make changes to your equipment / aids e.g. using a hoist will save wear and tear on your joints and will also conserve energy. If you are a walker, using a wheelchair part-time may have the same effect.
- Consider using a power wheelchair or e-motion wheels; both would preserve energy and protect your shoulder joints
- Try to be honest about your situation with friends and family, so they understand your limitations, and don't be afraid to say "no, I can't" on occasions
- Talking to other SCI people about their experiences and how they cope can be motivating and help to prevent you feeling isolated
- Try to plan something you will look forward to each day, even something small like a favourite TV or radio programme. When you're feeling happy and positive you usually feel more energised
- Walkers should consider using a wheelchair, to preserve energy and for your general safety, especially in crowded places.

Devising a daily routine

It can sometimes feel like there is no escape from life's daily routines, short cuts tend not to be an option, but considering how to reduce the frequency of certain tasks could be e.g. how many times you transfer in the day, and if you work full time, can you work part-time or would your employer allow you to work at home? Getting up and going to bed at the same time each day may help, although this may not always be possible, especially if your carer(s) is not able to stick to agreed timings. If your bladder and / or bowel management is taking too long, or is exhausting, you can seek advice about refining your regime from a Spinal Cord Injury Centre, Continence Specialist Nurse (employed by your GP Surgery) or the Bladder and Bowel Community (formerly the B&B Foundation): www.bladderandbowel.org/

Setting aside a period each day for rest and relaxation may be difficult to achieve, but it is worth trying. Turn off mobile phones and avoid other distractions such as computers and TV. Look at reducing the number of car journeys you make, to cut down on transfers, and if you lift your wheelchair into the car yourself you might consider introducing mechanical aids. Try shopping online occasionally, instead of going to the supermarket.

What are the options / methods of treatment?

- Medications to relieve symptoms e.g. pain management, sleep problems
- Counselling to help deal with feelings of guilt, anger and depression

Your GP can refer you to a counsellor but if you are looking for yourself, always ensure that the person you see is registered with one of the professionally recognised bodies e.g. the British Association of Counsellors and Psychotherapists: www.bacpregister.org.uk

- Cognitive Behavioural Therapy (CBT): this therapy helps you to manage your problems by changing the way you think, and ultimately the way you behave. To find a therapist go to the British Association of Behavioural and Cognitive Psychotherapists (BABCP) website: www.babcp.com

Seeking medical advice

- Seek specialist medical advice before fatigue starts affecting your daily routines
- Your GP may suggest blood tests to check for anaemia and underactive thyroid

Self Help

This doesn't always mean going it alone, you can still engage family and friends.



There are self-help books, including audio books, available online at Amazon.

Ask your GP or SCI consultant if there is a specialist clinic locally where you could get advice or treatment, and have your fatigue level monitored.

Complimentary Therapies

You may consider using complimentary (alternative) therapies on their own, or in conjunction with conventional treatments such as drug therapy. Listed below are some complimentary therapies, but please remember that such therapies will work for some people and not others, and there is generally a cost implication.

Some therapies may be difficult to access locally, such as hydrotherapy, and it is a good idea to source therapists where you have had a personal recommendation. Some people benefit from the therapies listed below, though for most it will have only a temporary beneficial effect:

- Massage
- Relaxation techniques
- Acupuncture
- Hydrotherapy
- Mindfulness (meditation)

When considering herbal medicine and supplements, care needs to be taken to confirm that the therapist is suitably qualified. Before taking any herbal remedies or supplements you should speak to a pharmacist to ensure that there is no likelihood of any adverse effects with treatments or prescribed medications that your GP has prescribed for you.

Support from family and friends is often very helpful, in addition to treatment and supervision from healthcare professionals.

Quality of life

Chronic fatigue, if left unchecked, can impact on many aspects of a persons' life. Living with a spinal cord injury may alter the way you prioritise and set goals, and cause you to reassess the things you value in life. You need to set realistic goals and learn how to pace yourself. Fatigue is one issue that you may have to adapt to, so that it has a minimal effect on the quality of your life. Keeping in touch with extended family and meeting up with friends can be energising, and don't be afraid to share your concerns with those closest to you; people are usually willing to help, particularly when they know how to support you. Steer clear of negative people who affect your mood, even if they do so unintentionally.

Summary

The key aspects of managing fatigue are recognising that it is a problem and then implementing the necessary changes and adaptations to minimise the impact it has on your life. Eating healthily, exercising within your capability, pacing yourself and making time for rest are all important. Equally, staying positive, involving family and friends, and assessment by the appropriate healthcare professionals will help in controlling your fatigue.

Further reading

Understanding Fatigue Sue Williams, Pages 28-30.

SCI and Fatigue Research Alina Palimaru and Marcus Dillistone, Page 31.

SIA Forward Magazine February 2016 No.131 Joy Sinclair Feb 2016

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.

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

W: www.spinal.co.uk

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Charity No: 1054097

Please support SIA



SIA relies on fundraising, donations and gifts in wills to provide services that help spinal cord injured people rebuild their lives.

With your help, we can provide the right support to spinal cord injured people and their families and friends so they can enjoy a full and independent life after injury. Your donation today will go towards changing someone's life.

I would like to give: £15 £20 £53 other amount £.....

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Please send your donation to: FREEPOST SPINAL INJURIES ASSOCIATION or you can donate online at www.spinal.co.uk

Thank you for your support!