FATIGUE
Introduction

Fatigue is a symptom rather than a condition, and it is all too common in today’s demanding world. It affects people of all ages, at any stage of life, and can be associated with lack of energy and motivation. Healthcare professionals sometimes find it difficult to distinguish fatigue from other common symptoms such as tiredness, and it often won’t be treated before it becomes chronic.

Fatigue in spinal cord injury (SCI) is under reported, under researched and not sufficiently understood. It can affect people of any age and females tend to be more affected than males. The level of injury appears to be relevant as well, with tetraplegics reporting more fatigue than paraplegics. These were the findings of a longitudinal study of 300 British SCI people who had been living with their injury for more than 23 years.

This fact sheet discusses some actions and techniques you should consider to help prevent and lower levels of fatigue and to avoid the problem becoming 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 it probably won’t go away on its own.

What causes fatigue?

Fatigue can be caused by a combination of factors.

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
- People who experience frequent episodes of autonomic dysreflexia.

Medications:
- Certain painkillers and muscle relaxants
- Alcohol and drug abuse

Other causes:
- Performing daily tasks
- Transferring many times during the day
Fatigue

• Pain
• Mood swings / anxiety / boredom
• Chronic headaches
• Sleep disturbances e.g. For bladder management or pressure relief.

The effects of fatigue
You may find you lack the energy and strength to perform your familiar routines, but avoiding essential tasks 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. People with incomplete injuries who are able to walk are just as likely to complain of fatigue as those with complete injuries, since walking with crutches or sticks can also lead to fatigue. Over time our muscle mass reduces and leads to increased weakness, which affects muscle function. Mood swings, memory and concentration lapses, can cause social isolation and affect relationships. Work and leisure activities may need adjusting, if possible consider reducing hours of employment.

Chronic Fatigue can result in:
• Memory problems
• Impaired concentration
• Sleep disturbances
• Weakness / dizziness.

Tips/actions 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 can record:
• How severe you feel your fatigue is – devise a scoring system using a scale of 1-10
• Feelings of weakness – are these worse in the morning or evening?
• Is it related to physical activity?
• Is it related to your mood?
• What makes it better?

Make small changes to your daily routines using evidence from your diary. If you can identify what makes you tired and at what time of the day this 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 – getting the balance right for you between exercise, activity and rest

Exercise – the right type and quantity e.g. Yoga, Pilates, a physiotherapist could 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 eating smaller meals more regularly instead of large meals, which take of a lot of energy to digest

Experiment with relaxation techniques such as mindfulness. For some people, just 10 minutes a day can help them 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 will have the same effect.

Consider use of a power wheelchair or e-motion wheels, both would be ideal for preserving energy and protection of 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” on occasions

Talking to other SCI people about their experiences and how they cope can be motivating, and help prevent you feeling isolated

Try to plan something to look forward to each day, even something small like your favourite TV / radio programme. When you’re feeling happy and positive you usually feel more energized.

For walkers, consider use of a wheelchair, both for preserving energy and for your safety, especially in crowded places.

Devising a daily routine

It can sometimes feel like there is no escape from the daily routine. Taking short cuts is generally not an option, but considering how to reduce certain tasks could be.

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 carers are 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 current regime from your Spinal Cord Injury Centre, Continence Specialist Nurse, (employed by your GP Surgery) or the Bladder and Bowel Foundation:

www.bladderandbowelfoundation.org

Setting aside a time each day to rest and relax may be difficult to achieve, but worth trying. You can enlist the help of carers and partners. Turn off mobile phones and avoid other distractions such as computers and TV.

Look at reducing the number of times you make car journeys so as to cut down on the numbers of transfers you carry out in a day. If you lift your
wheelchair into the car yourself you might consider introducing mechanical aids. Try shopping on-line instead of going to the supermarket.

**What are the various 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 may 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. Eg British Association of Counsellors and Psychotherapists: [www.bacpregister.org.uk](http://www.bacpregister.org.uk)
- Cognitive Behavioural Therapy (CBT) – this therapy helps you 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](http://www.babcp.com)

**Seeking medical advice**
- Try to seek specialist medical advice before fatigue starts affecting your daily routines.
- Your GP may suggest a series of tests such as bloods, for anaemia and underactive thyroid.

**Self Help**
This doesn’t necessarily mean going it alone, you can still engage family and friends.

Consider using *on-line assessment tools like the Piper Fatigue Scale* [www.fatigue.feedbucket.com](http://www.fatigue.feedbucket.com) which is used for people with chronic fatigue syndrome and neurological conditions such as multiple sclerosis. There are also self-help books including audio books – you can browse Amazon for suitable books.

Ask your GP or SCI consultant if there is a specialist clinic / facility 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. Below are some complimentary therapies that you may consider. These therapies 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. Try to source therapists where you have a personal recommendation.

Some people benefit from the therapies below, though these tend to 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 make sure the therapist is suitably qualified. You should speak to your GP first to make sure there are no contraindications with any treatments or prescribed medications that you take regularly.

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 so 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 deal with and 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. Don’t be afraid to share your concerns with those closest to you. People are often willing to help particularly if they know how to support you. Steer clear of negative people who affect your mood, even if unintentionally.

**Summary**

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

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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
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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