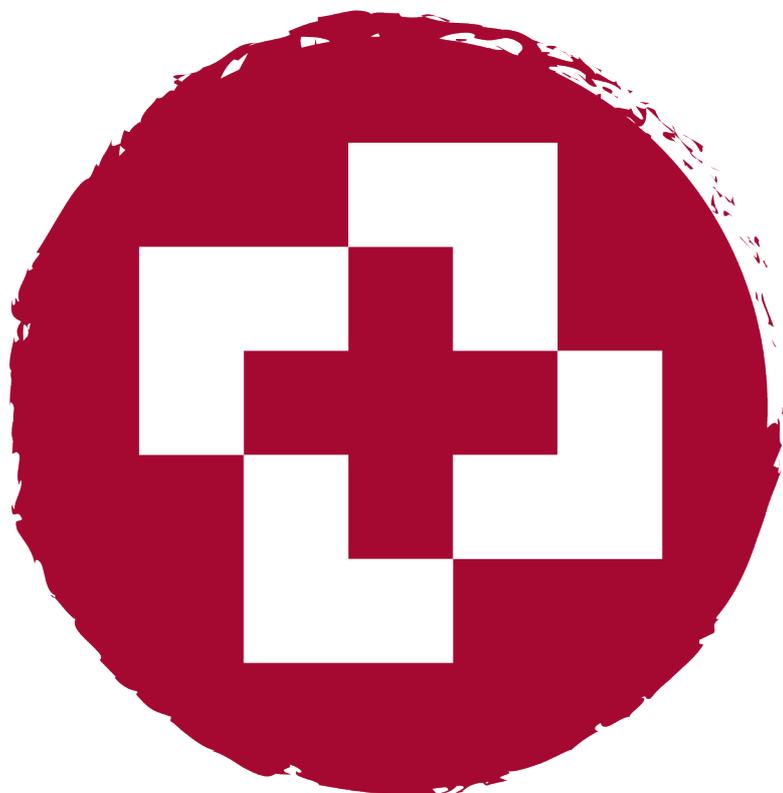


NHS CONTINUING HEALTHCARE

FACTSHEETS



EXAMPLE: RISK MANAGEMENT PROFILE

Risk Management

Autonomic dysreflexia -how it affects me

I develop a pounding frontal headache, become flush above my lesion level, clammy and distressed. To alleviate the symptoms in the first instance, I need to be sat up to induce hypotension, administer my GTN spray and take some baclofen and paracetamol. I then need to address the cause whatever that may be.

Once I have had a severe attack I can expect further, milder attacks for up to a month.

I do tend to get milder attacks on a unpredictable but regular basis. They can be induced via constipation and bladder infections which both occur regularly, particularly in the summer or if I let my diet or fluid intake slip.

Pressure sores-how it affects me

I have only had one pressure sore which was because of a shoe which had a seam in it. That was back in 1994 when I was hospitalised. I have been fastidious in managing my skin. I always use pressure relieving mattresses and I have a J2 cushion on my wheelchair. My wheelchair allows me to set back to alleviate pressure. Incontinence episodes are a constant hazard and they have been many occasions where I have had to return to bed or had my bedding changed. Nevertheless, pressure sores can develop within hours and as I get older I am noticing my skin is more problematical.

Obstructive sleep apnoea-how it affects me

I am currently being assessed about obstructive sleep apnoea. The tests have shown that I score 9/10 and I am just out of range. However, the consultant thinks I may have allergic rhinitis. I am therefore taking a steroid nasal spray and the antihistamines. Whilst this has helped I still have real issues with snoring and fatigue. I should point out that the snoring is a major issue for my wife. This situation is ongoing.

Maladministration-how it affects me

I keep very tight control of my drug regime. I avoid taking medications as much as possible for the simple reason that the more you take the more you seem to need and the less effective they become. Moreover, I believe that the continuity of care provided by my wife and my care team acts as an excellent safety net for me. In my experience, as soon as this continuity breaks down problems occur.

Choking- how it affects me

Last week, when I was going to bed something went down the wrong way. It wasn't food. In fact, I do not know what it was. I immediately was unable to breathe. Luckily my wife was on hand and gave me an assisted cough. Whilst not a common event, it is completely unpredictable and potentially lethal. Moreover, as a result of some food going down the wrong way a few years ago I developed double pneumonia which very nearly killed me. At

the same time I developed a DVT which also nearly led to my death. I am unable to cough or lean forward which helps when I need help with coughing and/or choking.

Temperature regulation-how it affects me

For me, temperature regulation has many facets. In the first instance, keeping warm during the day is always a problem and I generally feel uncomfortable. When I go to bed the symptoms are alleviated using quilts. However, it is very easy to overheat which in turn leads to other issues such as breathlessness. During the night it can be very difficult to get temperature regulation right. Generally speaking you either overheat or cool down each of which will lead to a break from my sleep which in turn means I have to wake up whoever is looking after me? Sometimes, if I overheat I can wake up panicking. This issue is therefore never resolved and intense, unpredictable and dangerous.

Postural hypotension-how it affects me

This is pretty much an everyday problem. It is particularly bad if I have had multiple bowel problems and/or sleeping issues. At its worst, my sight is affected I feel very dizzy and I am at risk of losing consciousness. The solutions are various dependent upon severity. Sometimes it can take several hours to recover. Last month I recorded my blood pressure during one such episode as 67/43.

Spasms-how it affects me

Totally unpredictable in their nature, cause and severity spasms are an intensive ongoing problem. I take painkillers and baclofen to alleviate the symptoms but at a cost. In particular, too much baclofen leads to drowsiness throughout the day and too little increases spasm frequency, severity and unpredictability. As the day progresses, I can find myself more and more slumped in my wheelchair. Moreover, sometimes my hips seem to be pulled over to one side which can lead to balancing issues. The main causes of the spasms tend to be UTI problems, bowel issues and anxiety.

Contractures and osteophyte development-how it affect me

As long as I can remember I have had a problem with drop foot and the range of movement in my left arm is severely limited. I do a full range of passive movements with my PAs regularly together with seeing a physiotherapist. Also, I stand using my wheelchair as regularly as possible. These procedures have multiple benefits but are time-consuming and I find them extremely tiring. Nevertheless, if I didn't do them, many issues would quickly escalate.

Osteoporosis-how it affects me

I was diagnosed with mild osteoporosis in my hips and number of years ago. I was instructed to take Fosamax on a weekly basis. However, my spinal consultant has advised me that he regards this as pointless. Who is right only time will tell? Incidentally, the above passive exercises/standing

frame exercises should help in slowing down the progression of this disease.

UTI-how it affects me

There are certain aspects which I do not want to discuss. After saying that, there are multiple issues which affect me. If I could find a solution to this infection my quality of life would be dramatically improved. I have had countless infections over the years and I've tried everything to counter them. Bladder washes, flip flow valves, prophylactic antibiotics on several occasions, numerous antibiotics, herbal remedies, huge volumes of fluids (generally speaking I drink 6 L per day) cranberry juice, colloidal silver etc etc. I have spoken to various doctors, consultants and participated in numerous forums. I have had MRSA at least twice, coliform infections and many many others. I am permanently infected. A bad night, a few drinks, a hot day, a journey even stress or anxiety all seem to lead to flareups. They exacerbate my spasms, they put me in a bad mood. They have hospitalised me. They are stressful for my family.

Chest infection/pneumonia- how it affects me

I have had pneumonia a few years ago. Also I have had a couple of chest infections together with throat problems.

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



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.

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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!