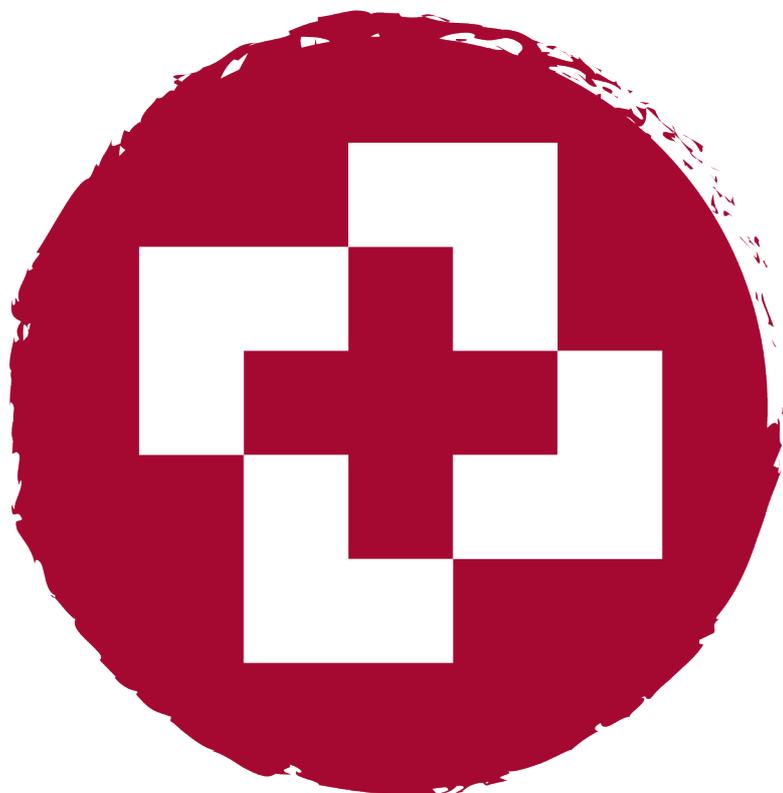


NHS CONTINUING HEALTHCARE

FACTSHEETS



EXAMPLE: ASSESSMENT PREPARATION

1. Breathing

Because of my tetraplegia my respiratory muscles are paralysed and I use my diaphragm to breathe. I am also unable to use my abdominal muscles. As my breathing is diaphragmatic it is shallow and I lack the ability to cough to clear my airways, chest or if I choke. I am therefore at risk of developing chest infections. When I have a cold or chest infection I require assistance to clear secretions. My carer has been specially trained to give an assisted cough. Because I am vulnerable to influenza and chest infections that could lead to pneumonia I have a flu jab every year.

I have asthma and currently use a preventer -once in the morning and once at night, I also use a reliever (Salbutamol) when needed. I use a spacer and because I have limited hand function my carer helps me with this. Sometimes I need to use my inhaler in the night and have to buzz my carer for assistance.

2. Nutrition

I require all my meals to be prepared and cut up into manageable pieces. I am able to feed myself using a hand splint to hold cutlery. My carers place a cup on the back of my hand so I am able to put this to my mouth.

Because I have a catheter it is important that I have a regular and copious fluid intake, my carer assists with drinks throughout the day and night.

I have been diagnosed with Irritable Bowel Syndrome and have changed my diet accordingly and now eat a predominately wheat free and low dairy diet. This has helped with my IBS but my bowel programme can still be unpredictable.

My weight is now fairly stable although it did get very low when I was depressed.

3. Continence

I am doubly incontinent. I have a suprapubic catheter which is changed every 6-8 weeks by my carers, my carers have had specialist training at Salisbury spinal unit and have also been trained in my home by specialist nurses from the spinal unit. I have developed an intolerance to latex catheters and now only use 100% silicone catheters. In the past year my catheter was very problematic and was blocking without warning and causing me to become dysreflexic very quickly (this is a medical emergency and requires immediate skilled intervention from my trained carers) because my catheter was blocking so frequently (every 3-4 days). I was admitted into the Spinal Unit in Salisbury for a Cystoscopy and bladder washout.

I have also undergone Urodynamics at the Spinal Unit and my bladder is now extremely small, because my bladder is so small if my leg bag is over full and urine backs up to my bladder I become dysreflexic very quickly. Occasionally my tubing on my leg bag gets twisted and my bladder will become over- distended which in turn triggers Autonomic Dysreflexia and requires skilled intervention. Six years ago I underwent Botox treatment for bladder spasms which were causing me to bypass urine, it was effective at the time but now I take Oxybutynin for bladder spasms. Occasionally if I have a particularly bad UTI I will bypass urine, at times like these my carers have to keep a careful eye on my skin integrity. If I am having symptoms of a UTI I will immediately up my fluid intake and drink extra cranberry juice, occasionally I am prescribed antibiotics particularly if a UTI is triggering Autonomic Dysreflexia. My carers also perform bladder washouts twice weekly.

My catheter site occasionally seeps discharge so my carer has to keep this clean and dry in order to maintain skin integrity, I also sometimes get over granulation of skin around my catheter site, this is treated with silver nitrate.

I am unable to empty my urine drainage bag myself so my carers do this for me, how fast my bag fills up is unpredictable so my carers keep a close eye on my drainage bag to avoid an over-distended bladder and possible Autonomic Dysreflexia attack.

During my period I use tampons and need my carers to assist me with this, occasionally during my period my normal bowel management is disrupted and I occasionally need to empty my bowel twice daily.

I have my bowel emptied every day my routine starts at 7.30am when my carer brings me a hot drink. At 8am my carer inserts two glycerol suppositories into my rectum and then transfers me onto the shower chair. On a typical day I need digital rectal stimulation and digital rectal evacuation of faeces from my bowel. My carer manually checks that my rectum is empty of stool, this is a skilled procedure which if not performed correctly can cause tears to the bowel lining, bleeding and/or Autonomic Dysreflexia. I have haemorrhoids and take Movicol every other day to keep my stools soft and to avoid constipation, however because of my IBS my bowel can be unpredictable sometimes an Autonomic Dysreflexia attack can be triggered, in this case we have to take the appropriate action.

Occasionally I have bowel leaks, in these instances my carer has to pay close attention to my skin integrity. After I have my bowel emptied my carer helps me wash in the shower. After showering I am transferred to the bed and dried off, my carer will check my skin and if necessary I will lie on the bed and wait for any red marks to fade.

4. Skin

Whilst in the Spinal Unit I developed a pressure sore on my natal cleft, it is now completely healed but occasionally the area goes red, (particularly during hot weather and occasionally during my period).

My carer is trained to spot any changes in my skin, she will check my skin before and after my bowel routine and also when I go to bed at night, I will take appropriate action if needed e.g. I will go to bed and stay off the mark or I will wear looser clothing if necessary. If I do need to go to bed for any reason, e.g. if I am ill or if I have a mark I will need to be turned frequently.

During the day my carer will reposition me in my wheelchair several times, this is not only for comfort but also to relieve pressure. My carer always ensures that my catheter tubing is positioned correctly and she also ensures that I am not sitting on any creases or seams. In the summer my carer will apply sun-cream, unfortunately last year because of my lack of sensation I burnt my toes in the sun and they blistered. A few years ago I burnt my arm badly on a radiator, I had to have my arm dressed regularly and now we are aware of the extra dangers.

I sleep on a soft foam mattress (recommended by the Spinal Unit) to minimise the risk of pressure sores, sometimes I need to buzz my carer during the night to reposition me. I sometimes need to have my legs repositioned during the night due to spasms and occasionally I will get cramps.

I sit on a Varilite cushion in my wheelchair, the cushion has a valve on it which regulates the air in the cushion, my carer adjusts the air in my cushion every morning when I first sit in it.

My carer cuts my toenails and ensures I do not have any in-growing toenails as this can cause infection and provoke Autonomic Dysreflexia.

My carer assists me to wash and cleanse my skin (especially after toileting or continence 'accidents') and hair as part of my daily personal care, she also ensures my catheter site is clean and dry. Occasionally I develop a rash around my catheter site, when this occurs my carer applies Elcon cream.

5. Mobility

I am paralysed and unable to walk. I am able to propel myself in the home but I need assistance from my carers when we go outside.

I have no trunk muscles and easily overbalance. On occasions I have fallen forward out of my chair, my carers are aware of this and occasionally have to grab me to stop me falling out. In the past I have fallen out of my chair when getting into my lift and also going around corners too fast.

I have leg spasms which can occur at any time throughout a 24 hour period. My carer will intervene by either applying pressure or by lifting my leg to stop the spasm. I also have spasms in my trunk which can knock me off balance. I take Baclofen which is effective but does not stop my spasms completely and I take Oxybutynin for bladder spasms.

I am transferred to and from bed to shower chair, bed to wheelchair, wheelchair to armchair and wheelchair to car by standing transfer carried out by my specially trained carer and we use a turning board because of my knee pain in my right knee. My carer ensures I am seated correctly and that I am not on any creases (to prevent pressure sores), she also checks that my catheter tubing is not kinked or digging into my leg (to prevent dysreflexia and pressure sores). My carers reposition me throughout the day, due to postural changes because of muscle spasms and also to make me comfortable and to ensure pressure relief to my skin.

Five times a week I use a standing frame for 30 –45 minutes, this improves digestion, circulation and minimises the risk of losing joint range of movement in my lower limbs, it also helps with my spasms. I require two carers to assist me into the frame and then one carer ensures my safety whilst in the frame.

In the late afternoon/evenings my carer transfers me into my armchair, this relieves the pain in my legs due to prolonged sitting and relieves skin pressure, I also raise my feet during this time because I suffer from oedema in my feet, ankles and calves. When I am in bed my carer makes sure I am positioned correctly and that I am not lying on any creases. I sometimes need to be repositioned during the night particularly during my period when my skin tends to be more sensitive and prone to marking or when my knee is particularly painful. If I am confined to bed (due to a mark on my skin, UTI, cold or dizzy periods) I need to be turned frequently, a pillow is used to ensure pressure sores do not develop. (Because of my immobility, the Mobility care needs interact with the Skin care needs).

I have an electrical stimulus implanted into my right hand which enables a pincer like grip. I am able to use a fork otherwise I have little control over my hands and fingers. I am unable to use my fingers for fine motor movements. In my left arm I have had a tendon transfer which enables me to raise my arm above shoulder level.

6. Communication

I am able to communicate verbally but use a buzzer at night to call my carer. However, during an episode of Autonomic Dysreflexia, poikilothermia, postural hypotension etc my ability to communicate may be compromised

7. Psychological / Emotional

I do have periods of anxiety and stress and have been diagnosed by my doctor in the past as 'depressed' I was prescribed medication, which I reacted badly to. I have now learnt relaxation and stress management techniques and use these when needed. With the help of my carers I make sure that I get out of my house everyday and participate actively in society. I use the library regularly and I am an active member of the Exmouth in Bloom Group.

During stressful periods I do suffer from back pain and stomach pain which in turn can affect my sleep patterns which then leads onto my bowel program being disrupted.

I think it should be noted that the months surrounding the review process are times when I do suffer badly with anxiety and stress, particularly because most assessors do not fully understand the nature, complexity, intensity and unpredictability of Spinal Cord Injury.

8. Cognition

My cognition can be compromised during episodes of sleeplessness, Autonomic Dysreflexia, postural hypotension, poikilothermia. My medication can also affect my ability to concentrate.

9. Behaviour

10. Drug therapies and medication

The drugs I take are:-

- a.** Baclofen - 10mg morning and night - to reduce muscle spasms.
- b.** Colpermin - one capsule 20 mins before eating - to reduce symptoms of IBS.
- c.** Glycerol suppositories - two every morning - to assist with my bowel routine.
- d.** Movicol sachets - one sachet every other night to soften stools and relieve constipation .
- e.** Oxybutynin - 10mg one per day to reduce bladder spasms

- f. Salbutamol - 100,micrograms/puff taken when needed to relieve asthma.
- g. Paracetamol - 500mg taken when required for pain.
- h. Nifedipine - 5mg capsules taken at the onset of Autonomic Dysreflexia to help to reduce a life threatening rise in blood pressure (during an attack of AD my specially trained carer not only administers Nifedipine she also has to find the cause and deal with it immediately)

I also take Vitamin C, cod liver oil, probiotics and cranberry juice.

I am dependent on my carer to administer all of my drugs because of my lack of manual dexterity.

I also stand regularly, (as mentioned previously) this helps with digestion, circulation, keeps my joints supple and also helps with my spasms.

11. Altered states of consciousness

I have very low blood pressure. Sometimes in the morning after going from lying to sitting in my shower chair I experience light-headedness, dizziness and sometimes feel faint, at times like these my carer will either tip me back in my chair or press on my stomach to raise my blood pressure. Occasionally I will experience these symptoms after having a large meal.

12. Any other significant needs

Autonomic Dysreflexia - Because of the level of my injury I am prone to attacks of AD. AD is unpredictable and can occur '*out of the blue*' and it progresses rapidly. AD is a medical emergency and is potentially life threatening. My carers have the skill, knowledge and training needed to be able to recognise the symptoms and to be able to resolve it quickly. My particular symptoms are that I sweat profusely above my SCI lesion, my skin gets blotchy, I get goosebumps and I get a severe pounding headache, I often become panicky and my carers need to 'take control' I **ALWAYS** carry Nifedipine (which my carers have to administer) and if I am a distance from home I carry the equipment needed to change my catheter. I also carry an alert card.

Autonomic Dysreflexia can be caused by a number of things such as:-

- a. **Inadequate bladder drainage** e.g. blocked catheter/urinary tract infection/urological procedures
- b. **Distended bowel**, insertion of suppositories, digital evacuation
- c. **Skin trauma**, e.g. ingrowing toe-nail, pressure sores Uterine contraction
- d. **Genital stimulation**
- e. **Any stimuli which could cause pain or discomfort.**

I am always at risk of an attack of AD and myself and my carers remain vigilant and ensure that my needs are well managed.

Because my condition is only really found in SCI it is highly probable that those treating me as an emergency admission to a hospital following an attack would not be knowledgeable about it or necessarily know how to recognize and deal with it.

f. Involuntary muscle spasms

I regularly experience spasms in my legs and trunk, my carers will often need to reposition me in my chair following spasms.

g. Temperature regulation

Because of my high lesion I suffer from poikilothermic syndrome this is related to my decreased ability to regulate body temperature. Because of my level of SCI I take on the temperature of my surroundings so I can quickly become hypothermic or pyrexial. As I do not sweat normally I may not realise that I am overheating and only become aware of the problem when starting to feel dizzy, faint or developing nausea, palpitations or 'seeing blue'. If I do become too hot or too cold I need assistance from my carer to regulate my temperature.

h. Risk awareness

I am unable to feel hot water, hot objects or pressure damage because of my SCI.

For further assistance please email: chc@spinal.co.uk

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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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 £.....

Method of payment

I enclose a cheque/postal order/CAF voucher made payable to Spinal Injuries Association.

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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!