

# NHS Continuing Healthcare

Information pack (revised August 2018)

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Produced by

*sia*

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injuries  
association

**FOR LIFE AFTER SPINAL CORD INJURY**



Revised August 2018

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## 1.0 INTRODUCTION

This information booklet has been updated following the revision by the Department of Health of '*The National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care*' in 2018. It supersedes the Continuing Healthcare Information Pack issued by the SIA Academy in 2013.

The revised framework came into effect in October 2018 for CCGs. The framework does not apply in Scotland, Wales or Northern Ireland.

The Welsh Assembly Government has issued separate National Framework guidance to Local Health Boards on implementing Continuing NHS Healthcare in Wales; this follows a similar structure to that in place in England, but has some differences, and will not be addressed in detail in this Information Pack.

This revised Information Pack has been written to help people with spinal cord injury (SCI) secure or retain an NHS Continuing Healthcare funded care package. Whilst aimed primarily at those with a tetraplegic lesion, there is, in principle, nothing to prevent people with paraplegia who have significant health care needs as a result of age or other concomitant health conditions, becoming eligible for NHS Continuing Healthcare, as it is the extent of your health care needs rather than your diagnosis that determines eligibility. It gives you guidance on how to prepare for and what to include in your Continuing Healthcare Assessment, and will help you maximise your chances of making a successful application.

## **2.0 NHS CONTINUING HEALTHCARE**

### **2.1 What is NHS Continuing Healthcare?**

*“...A package of on-going care that is arranged and funded solely by the NHS, where the individual has been found to have a ‘primary health need’...”. It can be provided in any setting.*

This definition of NHS Continuing Healthcare has been taken from The National Framework for NHS Continuing Healthcare and NHS Funded Nursing Care (2018) and establishes the principle that someone with a ‘primary health need’ is eligible for NHS funded care. However, the package of care that the individual receives is at the discretion of the Clinical Commissioning Group (CCG).

### **2.2 Who Is Eligible for NHS Continuing Healthcare?**

*“Where a person has been assessed to have a primary health need, they are eligible for NHS continuing healthcare and the NHS will be responsible for providing for all of that individual’s assessed health and associated social care needs, including accommodation, if that is part of the overall need. Determining whether an individual has a primary health need involves looking at the totality of the relevant needs.” (NF 2018 Para 54)*

Defining whether you have a primary social care need or health need is therefore the key determinant of who will arrange and fund your care. In many ways this is an artificial distinction because the two are so entwined and the boundaries are not easily defined. However, defining whether you have a ‘primary health need’ is the key driver for whether you will be eligible for NHS funded care.

If you are assessed as having a ‘primary health need’, then all of your assessed health and social care needs should be funded by the NHS, and will not be subject to a financial contribution from you. If your assessed need is primarily for ‘social’ care, however, then your care may be funded through your Local Authority (LA) Social Services Department, and will involve a means-test, resulting in a personal contribution unless you have very limited income and savings. If you have more than the current limit of £23,250 in savings, investments or certain other assets then you will be liable for the full cost of your social care package and be a ‘self-funder’.

### **2.3 What is a Primary Health Need?**

In simple terms an individual has a ‘primary health need’ if, having taken account of *all* their needs, it can be said that the main aspects or majority part of the care they require is focused on addressing and/or preventing health needs. The term ‘primary health need’ does not appear in primary legislation, but is a concept developed by The Secretary of State following legal test cases which sought to establish whether a person’s care was the responsibility of the NHS or of their Local Authority. One of these test cases involved Pamela Coughlan, a C5/6 (complete) tetraplegic person, living in an NHS-funded residential care setting, and so is particularly relevant to spinal cord-injured (SCI) people.

It was determined that a decision of ineligibility for NHS Continuing Healthcare is only possible where, taken as a whole, the nursing or other health services required by the individual;

*“(a) are no more than incidental or ancillary to the provision of accommodation which local authority social services are, or would be but for a person’s means, under a duty to provide; and*

*(b) are not of a nature beyond which a local authority whose primary responsibility is to provide social services could be expected to provide.” (NF Para 58)*

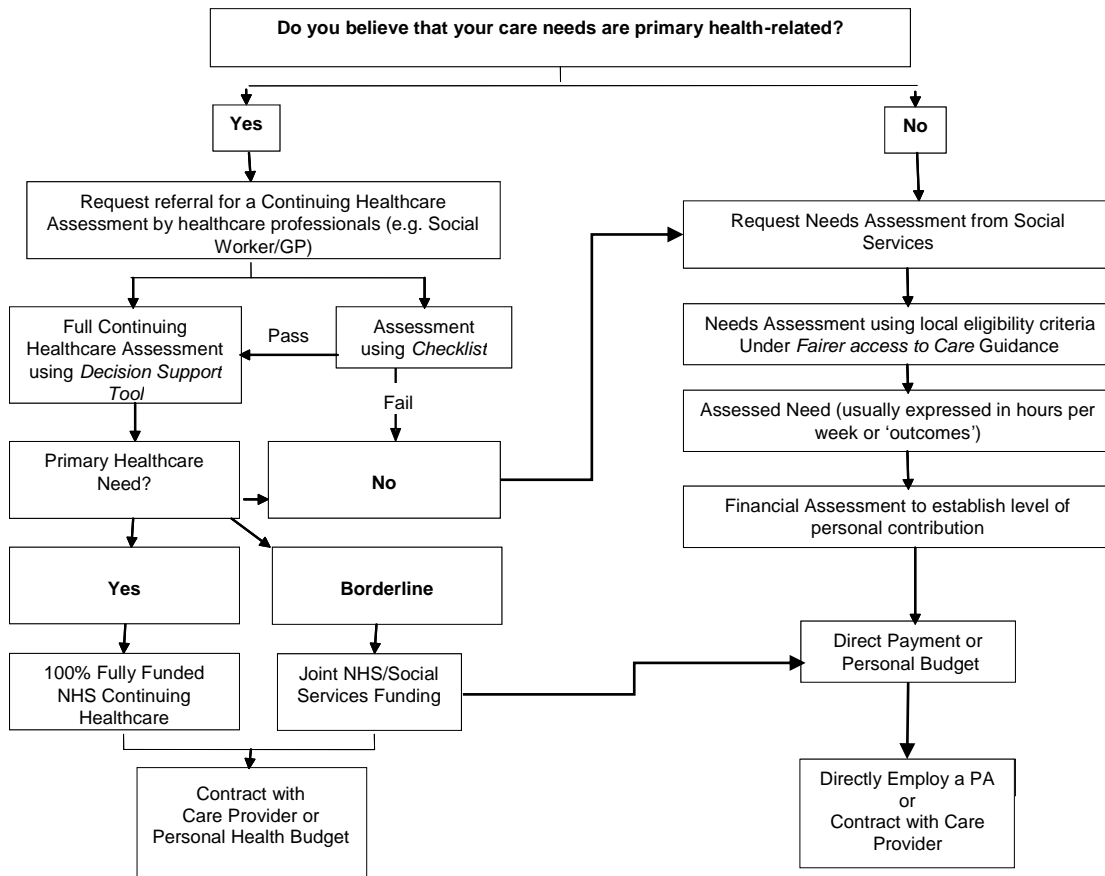
The Local Authority (LA) can only meet nursing/healthcare needs when, taken as a whole, the nursing or other health services required by the individual are below this level. If the individual’s nursing/healthcare needs, when taken in their totality, are beyond the lawful power of the LA to meet, then they have a ‘primary health need’.

## **2.4 Joint Funded Care Packages**

If a person does not qualify for NHS continuing healthcare, the NHS may still have a responsibility to contribute to that person’s health needs – either by directly commissioning services or by part-funding the package of support. This is because some individuals have needs (e.g. bowel care in SCI) which are of a nature that an LA cannot solely meet or are beyond the powers of an LA to solely meet. Where a package of support is commissioned or funded by both an LA and a CCG, this is known as a ‘joint package’ of care. A joint package of care could include NHS-funded nursing care and other NHS services that are beyond the powers of a LA. The joint package could also involve the CCG and the LA both contributing to the cost of the care package, or the CCG commissioning part of the package (National Framework 2012; Paras 263-269). In a joint funded care package, only the component funded by the LA is subject to a means-tested personal contribution.

### 3.0 The Assessment and Decision-Making Process

This chart summarises the process that should be followed if you decide to apply for NHS Funded Continuing Healthcare and starts with your request for a Continuing Healthcare assessment.



Establishing whether you have a ‘primary health need’ is done through an assessment of your care needs. If you are a newly injured SCI patient in an NHS hospital, this assessment will be carried out prior to your discharge. If, however, you are living in the community, an assessment may be prompted by a review of your care needs/funding by a Local Authority’s Social Services Department. An NHS Continuing Healthcare Assessment can also be requested by you via your GP, District Nurse or Social Worker.

Whether you are assessed prior to discharge or while living in the community the same assessment process must be followed.

### 3.1 Care Domains

The assessment looks at your care needs in 12 broad areas known as "Care Domains". These are:

1. **Breathing** needs relates to the effects of breathlessness, and requirements for supportive therapy such as oxygen, CPAP or tracheotomy.
2. **Nutrition (food & drink)** considers issues such as malnutrition, dehydration and aspiration
3. **Continence** considers level of need for both bladder and bowel management
4. **Skin (including tissue viability)** looks at any condition that has the potential to affect the integrity of the skin.
5. **Mobility** considers the needs of individuals with impaired mobility.
6. **Communication** needs relate to expression and understanding, not with the interpretation of language.
7. **Psychological & Emotional** needs are considered in relation to the impact on an individual's health & well being and how they impact on overall care needs
8. **Cognition** refers to individuals with a learning disability, an acquired or degenerative condition which places them at risk of self harm, neglect or exploitation
9. **Behaviour** assesses the level of challenging behaviour
10. **Drug Therapies & Medication** needs are determined by the intensity of symptoms and the knowledge & skill required to manage them. Also encompasses symptom control, including e.g. passive limb movements.
11. **Altered States of Consciousness** considers the level and consistency of consciousness.
12. **Other Significant Care Needs** is often used to categorise needs that do not easily fit into any of the other care domains. Examples include Autonomic Dysreflexia, choking and temperature regulation.

### 3.2 The Assessment Process

The assessment is usually done in two stages:

#### **Stage 1: Checklist**

The first part is a checklist and is intended to identify people who need a full consideration of whether they have a primary health need and qualify for NHS Continuing Healthcare. This stage can be carried out by a single practitioner, such as a GP, District Nurse or Social Worker.

The Checklist looks at your care needs in each of the 12 Care Domains in determining whether you should go forward for a full consideration of whether you have a primary health need. In the Checklist stage levels of care need are marked at three levels of need:

- A - Meets/exceeds the described need
- B – Borderline, nearly meets the described need
- C - Clearly does not meet the described need

Assessors are instructed that where the extent of a need may appear to be less because good care and treatment is reducing the effect of a condition, the need should be recorded in the

Checklist as if that care and treatment was not being provided.

To qualify for a full consideration (Stage 2) you must achieve a minimum score as follows:

- Two or more As or;
- Five or more Bs or;
- Four B's and one A or;
- One A in one of the four domains which carry a PRIORITY level in the Decision Support Tool. (These are Behaviour, Breathing, Drug Therapies & Medication Symptom Control and Altered States of Consciousness).

SIA believes all tetraplegics should satisfy this first stage and be entitled for a full consideration. This first stage is intended merely as a low-level filtering process.

You should receive a copy of the completed Checklist; if you don't, ask for a copy. If you are told you are not entitled to a full assessment (unlikely), you can ask the CCG to review that decision.

This stage may be skipped if a 'primary health need' seems likely.

### ***Stage 2: Full Assessment***

The second stage is the full assessment that will determine whether a recommendation of eligibility or ineligibility for NHS Continuing Healthcare is made. This stage is much more rigorous and must be carried out by an appropriately qualified Multi-Disciplinary Team (MDT) using what is known as the 'Decision Support Tool' (DST).

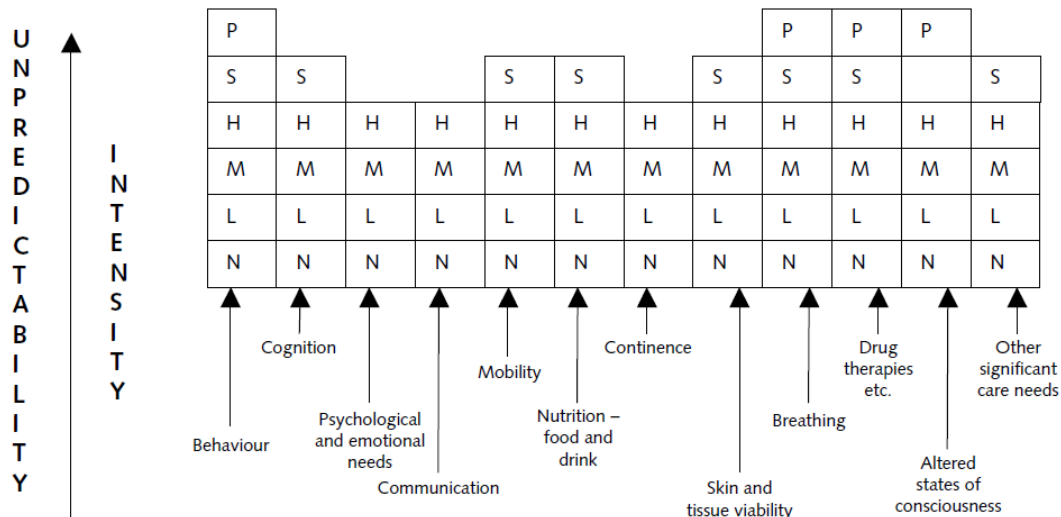
A Multi-Disciplinary Team must be made up of two or more qualified professionals. These professionals can come from different clinical and/or social care backgrounds. For instance, a Nurse Assessor from the CCG, an Occupational Therapist (OT), a District Nurse, a Physiotherapist, or a Social Worker. They will seek evidence of your health and social care needs from you and from people involved in your care (e.g. GP, Hospital Consultant(s), care provider) and should accept evidence (e.g. SIA Factsheets, your 48-hour Care Diary) from you too. They must also complete the Decision Support Tool and supply a copy of it to you.

In the second stage, the same twelve care domains are scored at up to six levels of need (Not all domains are scored against the highest two levels – see table below).

The levels of need are:

- P - Priority
- S - Severe
- H - High
- M – Moderate
- L - Low
- N - None





Identified needs can only score in one of the 12 care domains but can be referred to in the other domains; e.g. pressure ulcers would normally only score in the Skin and Tissue Viability domain but can be referred to in the Mobility domain if you need assistance with regular pressure relief. This "interaction" between the domains is important in illustrating the complexity of needs associated with SCI.

Although the tool supports the process of determining eligibility, and ensures consistent and comprehensive consideration of an individual's needs, it cannot directly determine eligibility. Indicative guidelines as to threshold for eligibility are set out in the DST (see below), but these are not (supposed) to be viewed prescriptively. Professional judgement should be exercised in all cases to ensure that the individual's overall level of need is correctly determined.

A clear recommendation of eligibility to NHS Continuing Healthcare would be expected in each of the following cases:

- A **priority** need in any one of the four domains that carry a priority level.
- Two or more domains where a **severe** need is identified.

A primary health need may well also be indicated if there is:

- One domain recorded as severe, together with needs in a number of other domains
- or**
- A number of domains with high and/or moderate needs.

In this second set of cases, the overall need, the interactions between needs in different care domains, and the evidence from risk assessments (if undertaken), should be taken into account by the MDT in deciding whether a recommendation of eligibility for NHS Continuing Healthcare should be made. It is not possible to equate a number of incidences of one level with a number of incidences of another level, for example two 'moderates' do not equal one 'high'.

It should be noted that as the threshold for eligibility has been set deliberately high by the Department of Health, our experience shows that very few people with SCI achieve a 'Priority' need and many tetraplegics do not readily achieve a 'Severe' need. It therefore becomes essential that you amass evidence to support such scores where feasible and assert your view of an appropriate score, and that where this is not achievable that as many 'High' and 'Moderate' scores as possible are recorded.

If needs in all domains are recorded as '**no need**' or '**low need**', this would indicate ineligibility (and would indicate failure to recognise your needs as an SCI person adequately). However, because low needs can add to the overall picture, influence the continuity of care necessary, and alter the impact that other needs have on the individual, all domains should be completed so as to maximise the scores achieved.

It is recommended that you familiarise yourself thoroughly with the Department of Health's publications on NHS Continuing Healthcare, including the National Framework for NHS Continuing Healthcare and NHS Funded Nursing care (revised) 2018, the Checklist and the Decision Support Tool <https://www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care> , as these give you useful information on how the assessment and decision making should be carried out (but sometimes is not!).

You can refuse to undergo an assessment for Continuing Healthcare, but this is likely to be counterproductive and we recommend that you participate actively in it (although you do not have to). Your informed consent should be sought, however, before commencing the process. You have a right to an advocate to help you participate in it.

### **3.3 The Decision Support Tool (DST)**

The DST should be completed by a multidisciplinary team, following a comprehensive multidisciplinary assessment of an individual's health and social care needs and their desired outcomes. The DST is not an assessment in itself.

#### ***What it is not – this needs to be emphasised –***

- *Another assessment*
- *A decision MAKING tool*
- *Suitable for every individual's situation*
- *A substitute for professional judgement*

Rather, it is a way of bringing together and applying evidence in a single practical format, to facilitate consistent, evidence-based decision making regarding NHS continuing healthcare eligibility. The evidence and the decision-making process should be accurately and fully recorded. The DST is designed to ensure that all of the factors that have a bearing on your eligibility are taken into account in reaching the decision.

The DST should not be used mechanistically (although in practice it usually is) and is not a substitute for professional judgement, and cannot directly determine eligibility. Nevertheless, how the assessors score your needs against each care domain will play a large part in determining your eligibility so you need to give thought and input to its completion. The assessors and the CCG are looking for evidence of whether the nature and/or complexity and/or intensity and/or unpredictability of a person's needs are such that the individual has a 'primary health need'.

'Nature' describes the particular characteristics of an individual's needs (which can include physical, mental health, or psychological needs), and the type of those needs. This also describes the overall effect of those needs on the individual, including the type ('quality') of interventions required to manage them. Assessors are advised that "it may be easier to think about 'Nature' after you have thought about intensity, complexity and unpredictability", and that they should ask themselves questions like:

- How would you describe the needs (rather than the medical condition leading to them)? What adjectives would you use?
- What is the impact of the need on overall health and well being?
- What type of interventions are required to meet the need?
- Is there particular knowledge/skill required to anticipate and address the need? Could anyone do it without specific training?
- Is the individual's condition deteriorating/improving?

'Complexity' is about the level of skill/knowledge required to address an individual need or the range of needs. Assessors are told to ask themselves things like:

- How difficult is it to manage the need(s)?
- Are the needs interrelated?
- Do they impact on each other to make the needs even more difficult to address?
- How much knowledge is required to address the need(s)?
- How much skill is required to address the need(s)?
- How does the individual's response to their condition make it more difficult to provide appropriate support?

'Intensity' relates to both to the extent ('quantity') and severity ('degree') of the needs and to the support required to meet them, including the need for sustained/on-going care ('continuity'). Assessors are advised to ask themselves things like:

- How severe is this need?
- How problematic is it to alleviate the needs and symptoms?
- How often and for how long is each intervention required?
- How much care is needed?
- How many carers are required?
- Does the care relate to needs over several domains?

The term 'unpredictability' describes the degree to which needs fluctuate and thereby create challenges in managing them. It also relates to the level of risk to the person's health if adequate and timely care is not provided. Someone with an unpredictable healthcare need is likely to have either a fluctuating, unstable or rapidly deteriorating condition.' Assessors are told to ask themselves things like:

- Are you able to anticipate when the need(s) might arise?
- Does the level of need often change? Do you often have to change the level of support at short notice?
- Is the condition unstable?
- What happens if you don't address the need when it arises? How significant are the consequences?

- To what extent is professional knowledge/skill required to respond spontaneously and appropriately?
- What level of monitoring/review is required?

The DST, combined with practitioners' own experience and professional judgement, should enable them to apply the primary health need test in a way that is consistent with the limits on what can lawfully be provided by a Local Authority, in accordance with the *Coughlan* and the *Grogan* judgments (see Appendix 1).

### **3.4 The Decision-Making Process**

Once the multidisciplinary team (MDT) has reached agreement, it should make a recommendation on eligibility to the CCG.

Many CCGs use an 'eligibility panel' to ensure consistency and quality of decision making. Only in exceptional circumstances, and for clearly articulated reasons, should the MDT's recommendation not be followed. It follows from this that unless you can convince the MDT to recommend eligibility you will not secure Continuing Healthcare; even if you are successful in doing so, SIA's experience is that CCGs/Panels frequently challenge or reject eligibility recommendations in practice, and you should be prepared for this. This is despite clear instruction that the Panel's (where these exist) role should be to:

- Confirm MDT decision on eligibility based on DST
- Examine whether DST fully completed and evidenced
- Ensure consistency and quality of decision making

and that eligibility panels should **not** have function of:

- Financial gate keeping
- Completing/altering DSTs
- Overturning recommendations (unless exceptional)

In arriving at a recommendation of eligibility the MDT, and in confirming it the CCG:

*"should be aware of cases that have indicated circumstances in which eligibility for NHS continuing healthcare should have been determined, and where such an outcome would be expected if the same facts were considered in an assessment for NHS continuing healthcare under the National Framework (e.g. Coughlan or those cases in the Health Service Ombudsman's report on NHS funding for the long-term care of older and disabled people)"* (National Framework, para. 157).

This is particularly relevant to people with SCI as Ms Coughlan (whose case is alluded to above) has a C5/6 (complete) tetraplegic lesion and is eligible for NHS Continuing Healthcare. SIA has a summary of Ms Coughlan's needs and you can view a video of her describing them at [www.nhscare.info](http://www.nhscare.info) .

This has all the more force, since the Court of Appeal in *Coughlan* considered that she *"...needed services of a wholly different category..."* to that which social services could lawfully provide, and therefore falls well within the eligibility criteria for NHS continuing Healthcare.

The National Framework (para. 157) cautions CCG's that they should be wary of trying to draw generalisations about eligibility for NHS Continuing Healthcare from the limited information they may have about Ms Coughlan, but because of our understanding of SCI, SIA is of the view that if your care needs and neurological impairment are comparable to or exceed those of Ms Coughlan, and those needs are evidenced adequately, you ought to secure a recommendation of eligibility.

It is therefore in your interests to ensure that the DST is fully evidenced and completed. Ensure that you have been given the opportunity to contribute to the DST, and that your views are appropriately recorded. You are entitled to a copy of the DST, which you should examine before it goes to Panel/CCG and only sign it if you are content that it represents a fair assessment of your needs.

## 4.0 Care Commissioning

Historically, 100% NHS-funded Continuing Healthcare funding usually necessitated contracting with a domiciliary care provider ('care agency') or nursing home, because NHS funding was not available as a Direct Payment in the same way that LA social care funding is.

There is now another option called a Personal Health Budget (PHB) which allows you to retain a greater say in who provides your care.

There are three ways in which a PHB can be delivered;

- 1. Notional budget.** No money changes hands. You find out how much money is available and talk to your local CHC team about the different ways to spend that money on meeting your needs. They will then arrange the agreed care and support.
- 2. Real budget held by a third party.** A different organisation or trust holds the money for you and helps you decide what you need. After you have agreed this with your local CHC team, the organisation then buys the care and support you have chosen.
- 3. Direct payment for healthcare.** You get the cash to buy the care and support you and your local CHC team decide you need. You have to show what you have spent it on, but you, or your representative, buy and manage services yourself.

CCG's contracting with a care provider is also an option for jointly-funded care packages, although the NHS may pass their contribution to LA Social Services Department so that it can be included as part of a Direct Payment (DP) or Personal Budget. This is legal so long as there is a residual community (social) care need, even if the overall care package is funded mainly by the NHS, (although not if the care package is 100% Continuing Healthcare funded).

If you are assessed as having 'Low' or 'No Needs' across the various care domains then your assessed need is primarily for 'Social' care and you will be referred back to the Social Services Department. Your assessment here will be carried out under Fair Access to Care Services Guidance and Local Eligibility Criteria. Any LA funding will be subject to a financial assessment to establish whether you are required to make a financial contribution towards your social care costs. Currently you will have to pay the full cost of your care if you have savings over £23,250 or a high income from a pension (but not from earned income). However your social care is funded, your care may be organised by you through a Direct Payment or Individual Budget. This can be used to directly employ carers or by contract with a Care Provider or a combination of the two.

In view of the economic situation, both LA and NHS CCG budgets are constrained, and whichever way you are funded it has become much harder to secure (and to retain) an adequate care package. Increasingly, LAs and CCGs are seeking to limit the cost of care packages in your own home to approximately the cost of a nursing home placement, which is usually insufficient to fund 24/7 care. It is very important, therefore, that you prepare a good case for arguing your needs.

## 5.0 The Pro's and Con's of NHS Continuing Healthcare

Depending on your financial circumstances and current care arrangements, a significant benefit of NHS funded Continuing Healthcare is probably financial. Unlike care funded by an LA, NHS-funded Continuing Healthcare is not subject to means testing.

If your care package is to be delivered by a care provider ('care agency'), you should consider making a case for a care provider that specialises in providing care for people with SCI, including bowel care. However, as the care package provided is that which your CCG assesses is appropriate for your needs, they may be resistant to this (e.g. cite cost or the agency not being on its 'preferred provider list' of providers). This means that your care may not necessarily be with your preferred care provider or indeed for as many hours as you need because of a CCG's desire to constrain spending on Continuing Healthcare. Moreover, SIA is aware of CCG's insisting that bowel care be delivered by District Nurses, even when an existing PA care team has been delivering bowel care satisfactorily for some time. If you encounter this issue and do not want your bowel care delivered by District Nurses, whose times of attendance may constrain your ability to participate in other activities, contact SIA for advice.

SIA is aware of instances where members have been pressurised to go into residential/nursing care as this will usually be a cheaper option for the CCG than being cared for at home; unless this accords with your wishes, you should resist this forcefully and seek advice from SIA's Advocacy Team.

NHS Continuing Healthcare does not have to be provided by specialist staff. It can be provided by a range of appropriately trained staff – the NHS recognises that family carers and relatives often provide some of the most sensitive and 'specialist' care along with home carers, nursing assistants and others. Who provides the care should not be used to decide whether an individual is eligible for NHS Continuing Health Care.

There are potential benefits of having your care delivered via a domiciliary care provider. These include the security of cover for your care at times when your staff have sickness or are otherwise absent, and the removal of your legal responsibilities as an employer, which can sometimes be onerous/problematic with directly-employed PA's.

## 6.0 PREPARING FOR YOUR ASSESSMENT

This section is intended to give you some guidance on how to prepare for and what to include in your Continuing Healthcare assessment. Whilst every individual will be different, it is hoped that by using the following notes you will not forget anything that could help you secure Continuing Healthcare funding.

It is useful to bear in mind that the assessment process has been designed to cover a wide range of impairments and not just Spinal Cord Injury. The needs associated with SCI don't always fit easily within the care domains. You should therefore try and think of your needs in the context of the care domains.

Preparing carefully and thoroughly for your assessment is critical. It is important to study each of the Care Domains against which you are going to be assessed and establish a target score based on your own knowledge of your condition. You should prepare evidence so that you can justify your level of need – in this respect recording a **48 Hour Care Diary** prior to the assessment may be particularly helpful. Remember that unless carried out in an SCI Centre, you are likely to understand your care needs better than those carrying out the assessment. In this regard it is not unusual for the assessors to underestimate the **complexity, intensity and unpredictability** of your care needs.

All of the 12 domains used have been covered for completeness, although it is expected that some of these will have little significance for most people with SCI. Six domains are of particular significance. These are Mobility, Skin (tissue viability), Continence, Breathing, Drug Therapies & Medication and Other Significant Care Needs. A 'severe' or 'high' score in at least three of these should be achievable.

It is vitally important to understand the concept of a 'well-managed need'. It should be borne in mind that throughout the assessment process it is essential to ensure that whoever is carrying out the assessment clearly understands both your existing care needs and the full extent of the inherent risks attached to your condition. The fact that your needs are well-managed (if they are) is immaterial. Assessors are instructed that;

“The decision-making rationale should not marginalise a need just because it is successfully managed: well-managed needs are still needs. Only where the successful management of a healthcare need has permanently reduced or removed an ongoing need, such that the active management of this need is reduced or no longer required, will this have a bearing on NHS Continuing Healthcare eligibility.” (Para 142 of NF)

Assessors are further instructed that; “It is not intended that this principle should be applied in such a way that well-controlled conditions should be recorded as if medication or other routine care or support was not present (refer to Practice Guidance note 23 for how the well-managed needs principle should be applied). The multi-disciplinary team should give due regard to well-controlled conditions when considering the four characteristics of need and making an eligibility recommendation on primary health need (Para 59 of NF).



For instance, even if you have never had a major pressure ulcer/sore or any major skin problem since you left hospital, the fact that you have not is due to your vigilance and management of the on-going risk, but there is an ever present risk that you could develop such skin problems at any time (up to 80% lifetime risk of pressure ulcer). For that reason it is essential that your skin, (especially pressure areas), is checked regularly, and as a minimum at least twice every day. You also need to ensure that you get on-going or regular pressure relief throughout the day.

The concept of a 'well-managed need' is equally relevant for patients being assessed for NHS Continuing Healthcare prior to discharge from a SCI Centre (or other hospital) where care should be of a very high standard, and thus the patient would not be expected to develop e.g. a pressure sore in that environment. In this context, the health care needs of the patient should be considered in terms of their future life in the community where care may not be optimal.

Finally, you need to focus not on days when you feel and cope well, but on the days when the unpredictable happens (e.g. bowel accident, catheter blockage, urinary tract infection). It may seem strange that for an organisation that promotes independence and self-reliance, SIA is advocating in this instance that you stress your dependence on others to highlight your vulnerability. This is not a reversal of our ethos, rather it is to ensure that the inherent, ever present risks that every person with SCI lives with every day of their lives are made abundantly clear to whoever is carrying out the assessment and to those who will make the final decision. It is important to remember that it is highly unlikely that your assessors fully understand the nature, complexity, intensity and unpredictability of Spinal Cord Injury (SCI) and the real health risks each of us runs every day.

## **6.1 THE 12 CARE DOMAINS AND WHAT TO CONSIDER**

The rest of these notes will take you through each of the twelve care domains and provide tips on how you can maximise your needs score in each. You should use these notes in conjunction with the Decision Support Tool (DST), which will be the 'tool' that will be used ultimately to inform the recommendation of eligibility/ineligibility.

## Decision Support Tool for NHS Continuing Healthcare Section 2 – Care Domains

Please refer to the user notes

### 1. Breathing

Description	Level of need
Normal breathing, no issues with shortness of breath.	No needs
Shortness of breath which may require the use of inhalers or a nebuliser and has no impact on daily living activities. <b>OR</b> Episodes of breathlessness that readily respond to management and have no impact on daily living activities.	Low
Shortness of breath which may require the use of inhalers or a nebuliser and limit some daily living activities. <b>OR</b> Episodes of breathlessness that do not respond to management and limit some daily living activities. <b>OR</b> Requires any of the following: <ul style="list-style-type: none"> <li>• low level oxygen therapy (24%).</li> <li>• room air ventilators via a facial or nasal mask.</li> <li>• other therapeutic appliances to maintain airflow where individual can still spontaneously breathe e.g. CPAP (Continuous Positive Airways Pressure) to manage obstructive apnoea during sleep..</li> <li>•</li> </ul>	Moderate
Is able to breathe independently through a tracheotomy that they can manage themselves, or with the support of carers or care workers. <b>OR</b> Breathlessness due to a condition which is not responding to treatment and limits all daily living activities	High
Difficulty in breathing, even through a tracheotomy, which requires suction to maintain airway. <b>OR</b> Demonstrates severe breathing difficulties at rest, in spite of maximum medical therapy Or A condition that requires management by a non-invasive device to both stimulate and maintain breathing (bilevel positive airway pressure, or non-invasive ventilation)	Severe
Unable to breathe independently, requires invasive mechanical ventilation.	Priority

You rely on diaphragmatic breathing as your intercostal (chest) muscles are paralysed. This means you have severely reduced lung capacity and impaired ability to clear secretions. As a result you are very susceptible to

chest infections which also cause sleep deprivation. In the event of any secretions you would require an assisted cough to be carried out by your carers. Your reduced lung capacity may well cause episodes of breathlessness that limit your daily activities. If this is the case it would quite clearly fulfil the Moderate level of need criteria.

You may suffer from obstructive sleep apnoea (OSA), where your airway closes and you stop breathing momentarily during your sleep. It results in oxygen depletion, fatigue and daytime-drowsiness. It can lead to cardiovascular morbidity if untreated. Tetraplegics have a higher incidence of OSA than the general population. Signs of this might be having a thick neck, excessive snoring, restless sleep every night, and drowsiness during the day. If you haven't been diagnosed with OSA, but recognise some of the symptoms, you should consult your GP.

The normal treatment for OSA is a Continuous Positive Airway Pressure (CPAP) or an **APAP** (Auto-adjusting Positive Airway Pressure) machine. At night the sufferer wears a mask over their nose (or nose and mouth) through which they breathe whilst asleep, and CPAP helps keep their airway open by applying a constant air pressure into their windpipe, preventing it closing. If you use a CPAP machine, this will automatically score as a 'Moderate' need (*Interaction with 'Breathing' domain*)

*Note: prior to DST revision in 2009, CPAP use justified a 'High' score. However, if tetraplegic you need to point out that, unlike non-SCI patients, because of your impaired/non-existent hand function you are unable to fit, adjust, or remove your mask, and cannot check for air leaks or clean the mask/pipe or fill the humidifier chamber with water (if used), and so your care needs exceed those of a non-tetraplegic person with this condition.*

Those who suffer from OSA may find their daytime cognition impaired. Such things as mask leak, inability to tolerate the mask due to such things as nasal congestion or having a cold, can lead to inadequate/poor quality sleep, which can result in memory loss, drowsiness etc., the next day (*Note: Interaction with 'Cognition' domain*)

You should achieve a 'High' score if you are able to breathe independently through a tracheotomy that you can manage yourself, or with the support of carers or care workers, but if you have a tracheotomy through which you still find it difficult to breathe and which requires suction to maintain your airway, you should automatically score 'Severe' in this domain.

Any other medical condition or medication pertaining to breathing (e.g. asthma, chronic obstructive pulmonary disease) should be mentioned.

*Note: that Ms Coughlan (Appendix 1) had no night-time breathing issues, but did use a 'corset' in the daytime to compensate for her breathing difficulties.*

*Note: Interaction with 'Cognition' and 'Breathing' domains.*

## Decision Support Tool for NHS Continuing Healthcare Section 2 – Care Domains

Please refer to the user notes

### 2. Nutrition – Food and Drink

Description	Level of need
Able to take adequate food and drink by mouth to meet all nutritional requirements.	No needs
Needs supervision, prompting with meals, or may need feeding and/or a special diet. <b>OR</b> Able to take food and drink by mouth but requires additional/supplementary feeding.	Low
Needs feeding to ensure adequate intake of food and takes a long time (half an hour or more), including liquidised feed. <b>OR</b> Unable to take any food and drink by mouth, but all nutritional requirements are being adequately maintained by artificial means, for example via a non-problematic PEG.	Moderate
Dysphagia requiring skilled intervention to ensure adequate nutrition/hydration and minimise the risk of choking and aspiration to maintain airway. <b>OR</b> Subcutaneous fluids that are managed by the individual or specifically trained carers or care workers. <b>OR</b> Nutritional status “at risk” and may be associated with unintended, significant weight loss. <b>OR</b> Significant weight loss or gain due to identified eating disorder. <b>OR</b> Problems relating to a feeding device (for example PEG.) that require skilled assessment and review.	High
Unable to take food and drink by mouth. All nutritional requirements taken by artificial means requiring ongoing skilled professional intervention or monitoring over a 24 hour period to ensure nutrition/hydration, for example I.V. fluids. <b>OR</b> Unable to take food and drink by mouth, intervention inappropriate or impossible	Severe

If you are fed via a PEG you should mention this within this domain.

If you are able to eat independently but require specialist equipment to do so ensure that the assessors understand this, and highlight the need for food to be cut up for you, if this is required.

If you need assistance with drinking this also needs to be reported and point out the importance of regular and copious fluid intake (2.5-4 litres daily) in order to reduce the risk of a urinary tract infection/catheter blockage and avoid constipation. How is fluid delivered to you when you are in bed?

If you have any special dietary needs you should points these out. If you are diabetic and control this by food, you should make this clear.

Weight, and the role nutrition plays in it, is another factor to consider. Excessive weight gain due to immobility may be an issue, interacting with several other domains eg difficulty in assessing skin integrity (*'Skin' domain*), pre-disposition to obstructive sleep apnoea, difficulty in transferring, moving and handling (*'Mobility' domain*) or catheter change (*'Contenance' domain*). Conversely, inadequate/poor nutrition and/or ability to maintain sufficient weights puts your skin integrity at risk (pressure sores/slow healing) and increases your susceptibility to hypothermia. Explain how you have lost muscle mass on legs and buttocks due to paralysis, as this may not be apparent to assessors who see a 'tetraplegic stomach' (apparent excess abdominal weight due to posture and muscle laxity).

Because your chest muscles are paralysed and you have a substantially reduced cough reflex you are potentially at a high risk of dysphasia (choking) that requires skilled intervention (assisted coughs) from your carers. Providing assisted coughs is a skilled technique that comes with significant risk (broken ribs) if not done correctly.

On this basis you may want to target a **high** level of need in this domain.

*Note interaction between; 'Skin', 'Breathing', 'Mobility' and 'Contenance' domains.*

## Decision Support Tool for NHS Continuing Healthcare

### Section 2 – Care Domains

Please refer to the user notes

### 3. Continence

Description	Level of need
Continent of urine and faeces.	No needs
Continence care is routine on a day-to-day basis; Incontinence of urine managed through, for example, medication, regular toileting, use of penile sheaths, etc. <b>AND</b> is able to maintain full control over bowel movements or has a stable stoma, or may have occasional faecal incontinence/constipation.	Low
Continence care is routine but requires monitoring to minimise risks, for example those associated with urinary catheters, double incontinence, chronic urinary tract infections and/or the management of constipation.	Moderate
Continence care is problematic and requires timely and skilled intervention, beyond routine care (for example frequent bladder wash outs, manual evacuations, frequent re-catheterisation).	High

You should automatically score a 'high' within this domain if you require manual evacuations.

However, if you do not manage your bowels using manual evacuations some assessors may argue that a well-managed bowel routine and use of penile sheaths or in-dwelling catheters will only score a 'moderate'. It is therefore important that you point out all the complications and risks associated with your continence care, the skills need in that care and that a well-managed need is still a need (*interaction with 'Psychological and Emotional Needs' domain*).

Assessors may try to score Autonomic Dysreflexia (AD) within this domain due to bowel and bladder care often triggering an episode. However most tetraplegics should be able to obtain a 'high' score within this domain without scoring AD here. In order to obtain a severe score in the 'Other significant Care Needs' domain we ask for it to be scored separately within that domain (for further information on AD please see 'Other Significant Care Needs' domain). However assessors should consider how AD interacts with your continence needs.

#### **Bowel Care**

Describe your bowel care needs in detail, and emphasise how long the procedure takes. Do you have a colostomy? If not, where is bowel care performed (on the bed/commode chair/toilet) Do you experience 'accidents' due to delayed bowel actions? If so, *note interaction with 'Skin'* due to skin faeces contact.

As previously indicated if your bowel care includes manual evacuation you should automatically receive a 'high' score in this domain. However you may use Peristeen or other type of anal irrigation system for your bowel care regimen, in which case you should emphasise that it too requires skilled administration. Digital rectal stimulation and digital removal of faeces are usually repeated several times and the care giver needs to manually check your

rectum is empty of stool. These are skilled procedures, which if not performed properly can cause tears to the bowel lining, bleeding and/or AD. Explain the complications that can occur as a result of the way your bowel care is managed (ie regular digital interventions use of enemas) including such conditions as rectal prolapse or haemorrhoids (piles) and how these complicate its management.

Emphasise the importance of not allowing constipation to develop (managed diet/fluid intake – *interaction with 'Nutrition' domain*) or use of eg Movicol/Senokot (*interaction with 'Drugs' domain*), as it can result in an impacted/distended bowel, which can trigger an AD attack or require hospitalisation. Bowel distention can also impair breathing in tetraplegics and high paraplegic lesions (due to the distended gut impinging on the diaphragm – *interaction with the 'Breathing' domain*).

## **Bladder Care**

Describe your bladder care (eg intermittent catheterisation/penile sheath/indwelling urethral or supra-pubic catheter/urostomy). If catheterised, your need for frequent (eg monthly/6 weekly) and sometimes unpredictable re-catheterisation or bladder washouts, which are health needs and require 'skilled intervention' that may go 'beyond routine care'. If a penile sheath user, its application/removal is similarly a health need. Explain what can happen if a catheter gets blocked/kinked or tubing of your sheath/urine drainage bag gets twisted or if the catheter 'flip-flow' valve gets left closed for too long. Explain how this can cause urine to back up into your bladder and cause it to become over-distended and how this can trigger autonomic dysreflexia (AD). Additionally, in men who rely on sheath drainage or in women who are not catheterised, 'residual volumes' of urine, due to impaired bladder emptying, may increase over time, particularly with ageing, increasing susceptibility to UTIs and AD.

Another possible consequence of a blocked catheter or twisted drainage tubing could be that there may be urine seepage around the catheter from an over-full bladder, or in the case of a penile sheath this may simply come off. In either case you would find yourself sitting in your own urine. If not dealt with immediately, this can increase the risk of skin irritation, leading to skin breakdown, and the possibility of a pressure sore.

*The interaction with 'Skin' domain needs to be emphasised, including need for care of a supra-pubic catheter site, which is at risk of maceration and tissue infection, and in men also of penile skin (e.g. maceration/balanoposthitis affecting penile foreskin can occur from prolonged sheath wearing). Removal of a penile sheath if not done carefully can also result in skin damage. Some female tetraplegics have to manage their bladder without using a catheter due to high sensitivity and tolerance issues, using incontinence pads, and 'accidents' occur requiring careful skincare management and manual handling for pad replacement (interaction with 'Mobility' domain).*

Many tetraplegics find it difficult to/cannot empty their own urine drainage bag while in their wheelchair/in bed, and the consequences of not having it emptied at appropriate times can lead to the same situation described above for a blocked catheter or twisted tubing. Stress that the need to empty your urine bag is unpredictable. For example, a problem that may occur as a result of the low blood pressure you experience when sitting up in your chair is a decrease in the amount of urine produced by the kidneys. You may notice that there is little or no urine in your urine bag, but after you recline, your leg bag may fill quickly. This is a result of the increase in your blood pressure that occurs when you lie down. Your carer needs to watch your drainage bag closely after changing positions to make sure it does not get too full. Some members may also require intermittent catheterisation, something most cannot do for themselves, so require someone who is trained to do it for them. The consequences of this not being done would be an over-distended bladder and a possible autonomic dysreflexia attack.

*Note: need for high fluid intake 2.5 – 4 litres/day and interaction with 'Nutrition' domain.*

People with SCI run a constant risk of contracting a Urinary Tract Infection (UTI) because of impaired bladder emptying/invasive procedures. A serious one can easily trigger autonomic dysreflexia in susceptible lesions. Most will contract a UTI periodically, often several in one year. Skill is required by both the SCI person and any carer in recognising the early symptoms and taking appropriate action. Chronic UTI warrants a 'Moderate' score, but your global continence needs warrant a 'High' score.

Although not a continence issue per se, if you are female and require assistance to cope with menstruation and use of tampons or pads, this domain is an appropriate point to refer to it. The menstruation cycle may interfere with normal bladder and bowel management, and may lead to 'accidents' of bladder and/or bowel. Those going through the menopause may also find their bladder and bowel management being disrupted.

The requirement for assistance with safe and hygienic disposal of clinical waste relating to your continence needs should also be noted, as should the necessity to wash out/disinfect drainage bags if used more than once.

*Note: Interaction with 'Skin', 'Breathing', 'Mobility', 'Drugs' and 'Nutrition' and 'Other Significant Care Needs' domain*



## Decision Support Tool for NHS Continuing Healthcare Section 2 – Care Domains

Please refer to the user notes

### 4. Skin (including tissue viability)

Description	Level of need
No risk of pressure damage or skin condition.	No needs
<p>Risk of skin breakdown which requires preventative intervention once a day or less than daily without which skin integrity would break down.</p> <p><b>OR</b></p> <p>Evidence of pressure damage and/or pressure ulcer(s) either with 'discolouration of intact skin' or a minor wound.</p> <p><b>OR</b></p> <p>A skin condition that requires monitoring or reassessment less than daily and that is responding to treatment or does not currently require treatment.</p>	Low
<p>Risk of skin breakdown which requires preventative intervention several times each day, without which skin integrity would break down.</p> <p><b>OR</b></p> <p>Pressure damage or open wound(s), pressure ulcer(s) with 'partial thickness skin loss involving epidermis and/or dermis', which is responding to treatment.</p> <p><b>OR</b></p> <p>A skin condition that requires a minimum of daily treatment, or daily monitoring/reassessment to ensure that it is responding to treatment.</p>	Moderate
<p>Pressure damage or open wound(s), pressure ulcer (s) with 'partial thickness skin loss involving epidermis and/or dermis', which is not responding to treatment</p> <p><b>OR</b></p> <p>Pressure damage or open wound(s), pressure ulcer (s) with 'full thickness skin loss involving damage or necrosis to subcutaneous tissue, but not extending to underlying bone, tendon or joint capsule', which is/are responding to treatment.</p> <p><b>OR</b></p> <p>Specialist dressing regime in place; responding to treatment</p>	High
<p>Open wound(s), pressure ulcer(s) with 'full thickness skin loss involving damage or necrosis to subcutaneous tissue, but not extending to underlying bone, tendon or joint capsule' which are not responding to treatment and require regular monitoring/reassessment.</p> <p><b>OR</b></p> <p>Open wound(s), pressure ulcer(s) with 'full thickness skin loss with extensive destruction and tissue necrosis extending to underlying bone, tendon or joint capsule' or above</p> <p><b>OR</b></p> <p>Multiple wounds which are not responding to treatment.</p>	Severe

Another key domain for SCI, but one in which the criteria for a 'Severe' score are so demanding that only the most unfortunate would achieve them. Arguably, however, every SCI person with a complete lesion, but intact skin, would find themselves in that situation if their skin care need was not well-managed, and this is the key point. Like Ms Coughlan (Appendix 1) who required repositioning approximately 8 times per day, you need re-positioning, pressure relief 24/7, monitoring and vigilance to maintain skin integrity, but your **well-managed need is still a need** and assessors should recognise this.

Research suggests that people with a SCI have a lifetime risk of up to 80%, and an annual incidence of 30%, of contracting a significant pressure ulcer; the risk increases with age, and up to 8% will die as a direct consequence of one. As complete (and some incomplete) SCI lesions have 'anaesthetic skin', meaning no skin sensation (i.e. cannot feel), below the level of injury they have no awareness that a skin problem is developing. A major pressure sore can develop in a matter of hours. Treating this could require months of hospitalisation, as pressure ulcers take weeks or months to heal. They can lead to osteomyelitis (bone infection) and septicaemia (blood poisoning) and can kill.

Every SCI person, even with intact skin, should achieve at least a 'Moderate' score in this domain, which is described as:

*'Risk of skin breakdown which requires preventative intervention several times each day, without which skin integrity would break down.'*

**OR**

*'Pressure damage or open wound(s), pressure ulcer(s) with 'partial thickness skin loss involving epidermis and/or dermis', which is responding to treatment.'*

**OR**

*'A skin condition that requires a minimum of daily treatment, or daily monitoring/reassessment to ensure that it is responding to treatment'*

If you have a pressure sore, you may justify a 'High' or in extreme cases a 'Severe' score for this domain. If you have a pressure ulcer, explain how it came about and how it is being treated. In the case of an earlier pressure ulcer, although healed, it will have scar tissue which will always be a weakness and have a propensity to breakdown. Have you ever had to seek advice from a tissue viability nurse?

If your skin is intact, assessors may 'downplay' your level of need, but this is a classic example of 'a well-managed need' and should not detract from it being a need. You should direct assessors to 'The Prevention and Management of Pressure Ulcers' – In: 'Managing Spinal Cord Injury: Continuing Care', Chapter 23 (2006), available from SIA.

*Note: The DST states that it is not intended that the 'well-managed need' principle should be applied in such a way that well-controlled physical health conditions should be recorded as if medication or other routine care or support was not present. For example, where someone's skin condition is not aggravated by their incontinence because they are receiving good continence care, it would not be appropriate to weight the skin domain as if the continence care was not being provided*

However, explain how the need is managed. Do you need assistance from a trained care-giver to relieve pressure on the skin when sitting in your wheelchair? Someone must check your skin a minimum of twice daily (usually when getting dressed and when going to bed), they must be trained to know what they are looking for, and if a problem is identified you may have to have bed rest to allow healing with a need for further care. All pressure areas, eg ischial tuberosities ('sitting bones'), sacrum, heels, ankles, elbows and shoulder blades, should be checked for red marks or other blemishes, abrasions and any other sign of skin damage (including spots, bites, infection and in-growing toe-nails which you will not be aware of). Stress how care has to be taken with straps for urine drainage bags, clothing selection, (avoiding creases, seams etc), and in moving/handling you to avoid shear forces to your skin. You need to mention your need to be turned during the night and its frequency. Even if you can manage extended periods without turning, you need to emphasise what happens when you are ill, when your vulnerability to pressure is significantly increased. If you have to stay in bed for long periods because of illness or pressure ulcer you will need regular turning 24/7 and your need for all personal care also increases. *Note: interaction with 'Mobility' domain.*

Mention any bed (e.g. profiling) or specialist mattress or additional measures (eg pillows) used to help reduce skin pressure. Mention any special seating equipment that you require, eg pressure-relieving gel or air cushions such as Jay, Vicair or Roho. Explain why these are necessary – they all demonstrate the risk and vulnerability you have without them of developing pressure sores and are part of the way your need is managed.

Your Waterlow Score, or any other scale, for assessing your risk of a pressure sore should be recorded (see <http://www.judy-waterlow.co.uk>)

Your dependency on a care-giver/chiroprapist/podiatrist to cut your nails should be pointed out; especially as in-growing toenails can cause infection and provoke autonomic dysreflexia.

Finally, explain how you need assistance to shave (if applicable), to wash and cleanse your skin (especially after toileting or continence 'accidents') and hair as part of your daily personal care routine, and to clean/dress any wounds (including stoma sites – *interaction with 'Continence' domain*). Mention any topical medications applied to your skin (e.g. antifungal cream) or if you have been advised to use an emollient cream (e.g. Cetaben) instead of soap. If you suffer from uncontrolled sweating, you may need assistance to change clothing/bedding to protect your skin.

Note: *interaction with 'Drugs', 'Mobility' and 'Continence' domains.*

## Decision Support Tool for NHS Continuing Healthcare Section 2 – Care Domains

Please refer to the user notes

### 5. Mobility

Description	Level of need
Independently mobile	No needs
Able to weight bear but needs some assistance and/or requires mobility equipment for daily living.	Low
Not able to consistently weight bear. <b>OR</b> Completely unable to weight bear but is able to assist or cooperate with transfers and/or repositioning. <b>OR</b> In one position (bed or chair) for the majority of time but is able to cooperate and assist carers or care workers. <b>OR</b> At moderate risk of falls (as evidenced in a falls history or risk assessment)	Moderate
Completely unable to weight bear and is unable to assist or cooperate with transfers and/or repositioning. <b>OR</b> Due to risk of physical harm or loss of muscle tone or pain on movement needs careful positioning and is unable to cooperate. <b>OR</b> At a high risk of falls (as evidenced in a falls history and risk assessment). <b>OR</b> Involuntary spasms or contractures placing the individual or others at risk.	High
Completely immobile and/or clinical condition such that, in either case, on movement or transfer there is a high risk of serious physical harm and where the positioning is critical.	Severe

Because of your level of paralysis you are completely unable to brace yourself in the event of a fall. In addition your lack of ability to weight bear leaves you prone to osteoporosis. As a result even a fall from a low-level would result in serious physical harm, typically a broken leg or hip. In the event of this type of injury you could not be treated conservatively. You could not be put in a cast because of your anaesthetic skin (due to the risk of pressure ulcers – *interaction with 'Skin' domain*). So at the very least you would need an extended period of bed rest – with all of the associated increased care needs – and would most likely require surgical intervention (plating, pinning etc).

For older SCI lesions in particular, there is a higher risk of fragility fractures due to osteoporotic weakening of the bones. In order to counter osteoporotic changes due to lack of weight bearing on the legs and to minimise the risk of losing joint range of movement in your lower limbs you may have a standing programme using a standing frame/chair/tilt table. You need to ensure the assessor is aware of how many times a week this should happen and for how long. Other reported benefits of regular standing include; improving digestion and circulation and a

reduction in the incidence of urinary tract infection. You will probably require supervision from a trained carer for the duration of standing due to the risk of postural hypotension and potential autonomic Dysreflexia episodes (*interaction with 'Altered States of Consciousness' and 'Other Significant Care Needs' domains*), as well as assistance to use the equipment.

Additionally, you are at risk of losing the range of movement in lower limbs, and may therefore be dependent on daily passive movements performed by a care-giver. Upper limbs may also require daily active assisted and passive movements to maximise function, prevent contractures and/or alleviate muscle spasm. (Passive exercises and a standing programme are also *relevant/interaction to 'symptom control' in the 'Drug domain'*)

Due to your lack of trunk muscles you are unable to support yourself, and easily overbalance. If you use a lap strap to secure yourself in your chair ensure you are wearing it during the assessment.

Your positioning, both on the bed and in the wheelchair, is critical. This is not only necessary for maintaining your skin integrity and avoiding pressure ulcers, but also for avoiding long-term postural asymmetries (scoliosis, windswept hips etc) that would inevitably result in increased care needs and costly medical intervention. As somebody with a spinal-cord injury you are at an extremely high risk of developing pressure ulcers without skilled and timely care interventions. Indeed research shows that individuals with spinal-cord injury have an 80% chance of developing a serious pressure ulcer in their lifetime. The fact that you do not currently have a pressure ulcer due to incorrect positioning/insufficient pressure relief is yet another example of the fact that your care needs are well-managed (*interaction with 'Psychological and Emotional Needs' domain*).

If you suffer from oedema (fluid retention) in your feet, ankles and calves, point this out. If you wear surgical stockings to help alleviate this, say so. Explain that this is due to immobility in your lower limbs and how poor circulation can lead to skin problems, making skin damage/sores slow to heal.

Explain how you are transferred from bed to chair, chair to toilet or bath, to and from wheelchair to car, use of hoists, transfer board/sheets and slings should also be explained. Explain how many people are required to carry out these transfers and how many times a day it is required (taking into account the possibility of bowel/bladder 'accidents').

Therefore the severe risk of physical harm on movement or transfer and critical nature of your positioning places your care needs at the **Severe** level of need in this domain.

*Note: Interaction with 'Skin', Psychological and Emotional Needs', 'Drug Therapies and Medication: Symptom Control', Altered States of Consciousness' and Other Significant Care Needs' domains*

## Decision Support Tool for NHS Continuing Healthcare Section 2 – Care Domains

Please refer to the user notes

### 6. Communication

Description	Level of need
Able to communicate clearly, verbally or non-verbally. Has a good understanding of their primary language. May require translation if English is not their first language.	No needs
Needs assistance to communicate their needs. Special effort may be needed to ensure accurate interpretation of needs or additional support may be needed either visually, through touch or with hearing.	Low
Communication about needs is difficult to understand or interpret or the individual is sometimes unable to reliably communicate, even when assisted. Carers or care workers may be able to anticipate needs through non-verbal signs due to familiarity with the individual.	Moderate
Unable to reliably communicate their needs at any time and in any way, even when all practicable steps to assist them have been taken. The person has to have most of their needs anticipated because of their inability to communicate them.	High

Primarily you need to consider any communication difficulties you have in addition to your spinal-cord injury.

If you use environmental control systems, hearing aids etc these should be mentioned within this domain.

In the absence of additional communication needs you need to explain to assessors that your paralysis effects your whole body from the neck down, including all four limbs, this means:

- You are primarily or completely reliant on verbal communication and unable to gesture or use body language in anyway, as a result:
  - You are extremely limited in your ability to communicate explanations of how your care needs to be delivered (eg how to ensure that your clothing is arranged correctly, how to ensure that you are positioned correctly etc)
  - In the event of disruption to your speech ability (as a result of chest infection, UTI, episode of Autonomic Dysreflexia, loss of voice, use of CPAP due to obstructive sleep apnoea etc) you would be completely unable to communicate your care needs.
  
- You are reliant on diaphragmatic breathing and unable to shout or call loudly to summon assistance in an emergency (*interaction with 'Breathing' domain*)

- You are partially or completely unable to independently use the telephone, computer and other communication devices, as a result:
  - You would be unable to call for assistance in an emergency
  - You would be unable to independently communicate with healthcare professionals by any means other than face to face.
- You are partially or completely unable to take notes which can make remembering important information in regard to your health care need difficult.

As a result of these you are reliant on skilled carers who have a detailed understanding and are familiar with your care needs, and should your condition render you unable to verbally communicate they will be able to interpret your care needs.

On this basis you may want to target a **moderate** level of need in this domain.

*Note: Interaction with 'Breathing' domain*

## Decision Support Tool for NHS Continuing Healthcare Section 2 – Care Domains

Please refer to the user notes

### 7. Psychological and Emotional Needs

Description	Level of need
Psychological and emotional needs are not having an impact on their health and well-being.	No needs
Mood disturbance, hallucinations or anxiety symptoms, or periods of distress, which are having an impact on their health and/or well-being but respond to prompts and reassurance. <b>OR</b> Requires prompts to motivate self towards activity and to engage them in care planning, support, and/or daily activities.	Low
Mood disturbance, hallucinations or anxiety symptoms, or periods of distress, which do not readily respond to prompts and reassurance and have an increasing impact on the individual's health and/or well-being. <b>OR</b> Due to their psychological or emotional state the individual has withdrawn from most attempts to engage them in care planning, support and/or daily activities.	Moderate
Mood disturbance, hallucinations or anxiety symptoms, or periods of distress, that have a severe impact on the individual's health and/or well-being. <b>OR</b> Due to their psychological or emotional state the individual has withdrawn from any attempts to engage them in care planning, support and/or daily activities.	High

Primarily you need to consider any diagnosed psychological or mental health conditions in addition to your spinal-cord injury. If you are on any medication for anxiety or distress this needs to be pointed out (*interaction with 'Drugs' domain*).

Do you suffer from mood disturbance or emotional distress arising from frustrations of your physical limitations that have an impact on your health and/or wellbeing? Do you withdraw from attempts to engage in support, care planning and daily activities? Do you feel socially isolated arising from reluctance/inability to go out to meet people? Are you self-conscious about yourself, or your appearance? Any of these factors can be considered as demonstrating a need associated with this domain.

However even if you don't experience any psychological and emotional difficulties, it is probable that the only reason is, because you have a functioning care package in place, in other words your psychological and emotional state represents a well-managed need. SIA believes the assessors should consider what your psychological and emotional needs would be without any care provision in place at all.

Para 142 of the National Framework states:

*Paragraph 142 states that "the decision-making rationale should not marginalise a need just because it is successfully managed: well-managed needs are still needs. Only where the successful management of a health care need has permanently reduced or removed an ongoing need, such that the active*



*management of this need is reduced or no longer required, will this have a bearing on NHS continuing Healthcare eligibility."*

On this basis you may want to target a **high** level of need in this domain.

*Note: Interaction with 'Drugs' domain*

## Decision Support Tool for NHS Continuing Healthcare Section 2 – Care Domains

Please refer to the user notes

### 8. Cognition

Description	Level of need
No evidence of impairment, confusion or disorientation.	No needs
Cognitive impairment which requires some supervision, prompting or assistance with more complex activities of daily living, such as finance and medication, but awareness of basic risks that affect their safety is evident. <b>OR</b> Occasional difficulty with memory and decisions/choices requiring support, prompting or assistance. However, the individual has insight into their impairment.	Low
Cognitive impairment (which may include some memory issues) that requires some supervision, prompting and/or assistance with basic care needs and daily living activities. Some awareness of needs and basic risks is evident. The individual is usually able to make choices appropriate to needs with assistance. However, the individual has limited ability even with supervision, prompting or assistance to make decisions about some aspects of their lives, which consequently puts them at some risk of harm, neglect or health deterioration.	Moderate
Cognitive impairment that <u>could</u> include frequent short-term memory issues and maybe disorientation to time and place. The individual has awareness of only a limited range of needs and basic risks. Although they may be able to make some choices appropriate to need on a limited range of issues they are unable to consistently do so on most issues, even with supervision, prompting or assistance. The individual finds it difficult even with supervision, prompting or assistance to make decisions about key aspects of their lives, which consequently puts them at high risk of harm, neglect or health deterioration.	High
Cognitive impairment that <u>may</u> , for example, include, marked short-term memory issues, problems with long-term memory or severe disorientation to time, place or person. The individual is unable to assess basic risks even with supervision, prompting or assistance, and is dependent on others to anticipate their basic needs and to protect them from harm, neglect or health deterioration.	Severe

Primarily you need to consider any cognitive impairment you may have in addition to your spinal-cord injury.

This may apply, but not limited to, individuals with learning disability and/or acquired brain injury and degenerative disorders which places them at risk of self-harm, neglect or exploitation.

As with the behaviour domain, elderly people with SCI who develop dementia, or who have other neurodegenerative conditions associated with ageing, may find this domain carries greater importance than in the younger SCI population.

In the absence of a cognitive impairment, consider difficulties with disorientation and short-term memory. These may be caused by both ongoing and episodic issues:

- Ongoing Issues:
  - Impaired Sleep. If your sleep is impaired by your spasms which wake you up during the night and the need for your carers to reposition you both for comfort and to provide pressure relief and avoid developing pressure ulcers;
  - Medication Side-Effects. Both your antispasmodics and analgesics may have the side-effect of drowsiness and impaired cognition.
  
- Episodic issues:
  - Autonomic Dysreflexia. During an episode of Autonomic Dysreflexia you will have limited ability to assess basic risk and have difficulty in making your own decisions or choices, even with prompting and supervision.
  - Infections. Both urinary tract infections and chest infections can limit your ability to make appropriate decisions in respect of your care provision;
  - Postural Hypotension. (*See 'Altered States of Consciousness' domain*)

Because of the amount of detail in your daily care routine and the critical importance of both the content and the order of the tasks involved, even occasional cognitive difficulties can have a significant impact on your ability to effectively direct your care. This means that you rely on skilled carers with a detailed knowledge of your care who can anticipate your needs.

On this basis you may want target a **Low** level of need in this domain (unless there are other conditions that need to be taken into consideration as detailed above)

*Note: Interaction with 'Drugs' 'Altered States of Consciousness' and Other Significant Care Needs' domains*

## Decision Support Tool for NHS Continuing Healthcare Section 2 – Care Domains

Please refer to the user notes

### 9. Behaviour

Description	Level of need
No evidence of 'challenging' behaviour.	No needs
Some incidents of 'challenging' behaviour. A risk assessment indicates that the behaviour does not pose a risk to self, others or property or a barrier to intervention. The person is compliant with all aspects of their care.	Low
'Challenging' behaviour that follows a predictable pattern. The risk assessment indicates a pattern of behaviour that can be managed by skilled carers or care workers who are able to maintain a level of behaviour that does not pose a risk to self, others or property. The person is nearly always compliant with care.	Moderate
'Challenging' behaviour that poses a predictable risk to self, others or property. The risk assessment indicates that planned interventions are effective in minimising but not always eliminating risks. Compliance is variable but usually responsive to planned interventions.	High
'Challenging' behaviour of severity and/or frequency that poses a significant risk to self, others or property. The risk assessment identifies that the behaviour(s) require(s) a prompt and skilled response that might be outside the range of planned interventions.	Severe
'Challenging' behaviour of a severity and/or frequency and/or unpredictability that presents an immediate and serious risk to self, others or property. The risks are so serious that they require access to an immediate and skilled response at all times for safe care.	Priority

This domain relates to challenging behaviour, for most members they are unlikely to score very highly, however some members may have acquired a brain injury as part of their SCI and may be subject to irrational behaviour which may present themselves as fits of violent temper, resulting in either physical or verbal abuse, or may experience suicidal thoughts. Behaviour like this should be brought to the assessors' attention. For elderly people with SCI who develop dementia, or who have other neurodegenerative conditions associated with ageing, this domain may assume greater importance.

## Decision Support Tool for NHS Continuing Healthcare

### Section 2 – Care Domains

Please refer to the user notes

#### 10. Drug Therapies and Medication: Symptom Control

Description	Level of need
Symptoms are managed effectively and without any problems, and medication is not resulting in any unmanageable side-effects.	No needs
Requires supervision/administration of and/or prompting with medication but shows compliance with medication regime. <b>OR</b> Mild pain that is predictable and/or is associated with certain activities of daily living. Pain and other symptoms do not have an impact on the provision of care.	Low
Requires the administration of medication (by a registered nurse, carer or care worker) due to: non-concordance or non-compliance, or type of medication (for example insulin), or route of medication (for example PEG,). <b>OR</b> Moderate pain which follows a predictable pattern; or other symptoms which are having a moderate effect on other domains or on the provision of care.	Moderate
Requires administration and monitoring of medication regime by a registered nurse, carer or care worker specifically trained for the task because there are risks associated with the potential fluctuation of the medical condition or mental state, or risks regarding the effectiveness of the medication or the potential nature or severity of side effects. However, with such monitoring the condition is usually non problematic to manage. <b>OR</b> Moderate pain or other symptoms which is/are having a significant effect on other domains or on the provision of care.	High
Requires administration and monitoring of medication regime by a registered nurse, carer or care worker specifically trained for this task because there are risks associated with the potential fluctuation of the medical condition or mental state, or risks regarding the effectiveness of the medication or the potential nature or severity of side-effects. Even with such monitoring the condition is usually problematic to manage. <b>OR</b> Severe recurrent or constant pain which is not responding to treatment. <b>OR</b> Risk of non-concordance with medication, placing them at risk of relapse.	Severe
Has a drug regime that requires daily monitoring by a registered nurse to ensure effective symptom and pain management associated with a rapidly changing and/or deteriorating condition. <b>OR</b> Unremitting and overwhelming pain despite all efforts to control pain effectively.	Priority

Scoring in this domain depends on (i) medication usage, (ii) pain intensity you experience, (iii) or other means of symptom control (e.g. physiotherapy or passive exercises performed by your carer, hydrotherapy, use of standing frame/chair or tilt table to prevent contractures/slow demineralisation of your bones/alleviate spasm etc), and (iv) on the knowledge and skill needed to manage the clinical need.

Note that Pamela Coughlan did not require a regular programme of active or passive physiotherapy or exercise, although being assisted to stand twice per week 'assisted with maintaining appropriate organ positions and strengthening her bones'. All of her medication was routinely prescribed and administered by mouth (Senokot, Docusate, calcium, iron). Once her condition stabilised she did not require an allocated consultant nor require any interventions from 'specialist' healthcare professionals.

You should discuss all drug or other therapies you are currently receiving and explain how often and when these are administered. Stress your dependency on your carer to administer any treatment if you are tetraplegic due to lack of manual dexterity.

Medications or treatments include suppositories/enemas for your bowel care (if applicable), and agents to manage constipation (e.g. Movicol, Senokot). If you use Peristeen or other type of anal irrigation system for your bowel care regimen that should be cited here (Note: interaction with 'Continence' domain. Mention if you use daily low level antibiotic prophylaxis to reduce the risk of bladder infections. If you have a UTI or other infection you may need assistance to monitor your temperature. You may take Baclofen to control involuntary muscle spasms or have a Baclofen pump fitted. Don't forget complementary medicines (eg glucosamine for joint pain, cranberry tablets/juice for bladder care etc).

Don't forget to cross-reference with other domains (e.g. Baclofen with '*Mobility*' because of relevance of spasms to transfers, antibiotic prophylaxis for UTI with '*Continence*' and GTN spray or Nifedipine for autonomic dysreflexia with '*Other Significant Care Needs*').

If you require insulin injections to counter hypoglycaemia this should warrant a 'high' score due to the administration and monitoring of these drug regimens and the ongoing management of the condition requiring a nurse or trained carer to be knowledgeable, skilled and trained.

Chronic pain affects up to 82% of SCI people. If you experience chronic pain (e.g. neuropathic root pain), depending on its intensity, you may secure a 'high' or 'severe' score on that parameter alone, but it is the totality of your needs in this domain that should be considered overall. A 'Priority' score is unlikely.

*Note: Interaction with 'Continence', 'Mobility' and 'Other Significant Care Needs'*

## Decision Support Tool for NHS Continuing Healthcare

### Section 2 – Care Domains

Please refer to the user notes

#### 11. Altered States of Consciousness (ASC)

Description	Level of need
No evidence of altered states of consciousness (ASC).	No needs
History of ASC but it is effectively managed and there is a low risk of harm.	Low
Occasional (monthly or less frequently) episodes of ASC that require the supervision of a carer or care worker to minimise the risk of harm.	Moderate
Frequent episodes of ASC that require the supervision of a carer or care worker to minimise the risk of harm. <b>OR</b> Occasional ASCs that require skilled intervention to reduce the risk of harm.	High
Coma. <b>OR</b> ASC that occur on most days, do not respond to preventative treatment, and result in a severe risk of harm.	Priority

Because of your paralysis you are likely to suffer from postural hypotension. This typically occurs when going from lying down to sitting up in your wheelchair which precipitates a rapid drop in your blood pressure and leads to dizziness and fainting. When this occurs you are typically unable to direct your carers and they need to be able to recognise the onset of postural hypotension and take immediate remedial action (raising your legs or tipping your wheelchair back). If this action is not taken you would lose consciousness. Because this would happen in a sitting position there would not be a mechanism for your blood pressure to equalise and for you to regain consciousness. This could result in brain damage or even death.

Therefore as skilled intervention is required to reduce the risk of on that basis you may want to target a **High** level of need in this domain.

## Decision Support Tool for NHS Continuing Healthcare

### Section 2 – Care Domains

Please refer to the user notes

#### 12: Other significant care needs to be taken into consideration

Description	Level of need
	Low
	Moderate
	High
	Severe

In addition to the care needs in the other care domains you need to draw the assessor's attention to other care needs in relation to your spinal cord injury:

#### 1. Autonomic Dysreflexia

This condition is unique to patients with SCI above a T6 lesion. It results in uncontrolled raised blood pressure (systolic BP in excess of 200 mmHg can occur within minutes) and if the cause cannot be readily identified and dealt with carefully titrated pharmacological intervention is necessary to mitigate the risk of stroke or other cardiovascular incident. It occurs unpredictably at any time of day or night. It represents a medical emergency.

If you have not recently had a full-blown episode of Autonomic Dysreflexia it is only because your health care needs are well-managed. However the underlying risks associated with this condition can never be permanently reduced or removed. Incidents which could trigger an episode of Autonomic Dysreflexia are numerous, and relatively minor – but the consequences would be catastrophic if the necessary intervention was not provided immediately. It is important that it is rapidly recognised by those caring for you particularly as you may not recognise the build-up. You would probably be unable to self-medicate and might not be able to summon assistance.

#### 2. Temperature Control.

High-level tetraplegics typically suffer from Poikilothermic Syndrome (an inability to control your own body temperature) as a result your core body temperature tends towards the ambient temperature and you are at risk of both hyper and hypothermia. Because of this you are in part or wholly dependent on carers to compensate by managing your environment and clothing to counter the associated risks.

As a result you should be targeting a **severe** level of need in this domain.



Having addressed the twelve care domains, it is imperative that the four key indicator section is not overlooked, as often decisions of eligibility hinge on this section. The four key indicators are nature, intensity, complexity and unpredictability.

SIA suggest you consider if the following is relevant to you within each of these sections and ensure that your input is noted within the DST assessment;

### Nature

- Tetraplegia affects all bodily systems and causes complications which are unpredictable and potentially life threatening.
- Management of the condition requires frequent and unpredictable interventions over a 24 hour period, thus preventing complications and hospital admissions.

### Complexity

Because tetraplegia affects all body systems care needs identified in each of the 12 care domains cannot be considered in isolation as they impact on other domains;

- Lack of mobility and anaesthetic skin add significant complexity to skin management, as does continence management and the ever present risk of bladder and bowel accidents.
- Nutrition requirements have a direct impact on continence management because of the neurogenic bladder and bowel.
- Diaphragmatic breathing interacts with the ability to communicate health care needs.
- During an episode of autonomic dysreflexia cognitive and communication abilities would be severely impaired.
- Medication can affect continence due to constipation or cause drowsiness and these in turn can then have an effect on my psychological and emotional wellbeing

### Unpredictability

- Risk of unpredictable episodes of incontinence (urinary and faecal) necessitating immediate action to ensure skin integrity is maintained
- An Autonomic Dysreflexia attack would require urgent assistance to identify the cause and administer appropriate medication.
- Pressure relief is required on both a regular and unpredictable basis to maintain skin integrity and to relieve pain
- An individual with tetraplegia has virtually no effective ability to cough or clear their throat. Therefore all tetraplegics are at a high risk of dysphagia (choking) that requires skilled intervention (assisted coughs) from carers.

### Intensity

Tetraplegia necessitates assistance with all elements of care over a 24 hour period;

- All transfers will require hoisting or the use of other specialist equipment, often requiring two carers, these will be required on an unpredictable basis due to bowel/bladder accidents, feeling unwell, pressure relief etc.
- Regular monitoring of urinary output and drainage
- Bowel management will be required, often including manual evacuation, it should be noted that this type of bowel care alone goes beyond the ongoing competence of RGN's in District General Hospitals.
- Pressure relief will be required at regular intervals over a 24 hour period
- Skin needs to be checked at least twice daily for potential damage.
- If unwell a higher intensity of care will be required
- Due to susceptibility to Poikilothermia, an inability to adjust body temperature, and to avoid hypothermia and hyperthermia carers need to be available to adjust clothing and bedclothes accordingly.

## 6.2 Summary

A key to success will be thorough preparation on your part. Make sure you are familiar with the National Framework and Decision Support Tool. Record your daily routine, from the moment you wake up to going to bed at night. You can use a 48-hour Care Diary to align your care needs with the needs domains of the assessment process (*SIA's Advocacy Team can provide you with a draft copy if required*). Include in your list anything that has to be done for you during the day and night. Include everything, no matter how small or insignificant it may seem. If some things are only done intermittently or not every day, still include them. They all add to your overall need for care. The objective is to build a picture of the nature, intensity, complexity and unpredictability of your care needs associated with your spinal cord injury for both the assessors and members of the decision-making panel.

Make sure you give a copy of your Care Diary to the assessors and go through it with them, using it as a check to ensure nothing is overlooked. The assessors don't know your routine or fully understand your needs. The objective is to establish that your PRIMARY care need is for 'HEALTH' not 'SOCIAL' care. By establishing that, you have a 'primary health need' you **should** qualify for NHS Continuing Healthcare.

Assessors need to consider how different but interrelated needs across more than one domain can interact to complicate the individual's overall care needs..

Where the assessors cannot agree on a level of need in any of the care domains they are guided:

### **Para 33.1 Practice Guidance**

*'The DST (paragraph 21 of the user notes) advises practitioners to move to the higher level of a domain where agreement cannot be reached but there should be clear reasoned evidence to support this. If practitioners find themselves in this situation they should review the evidence provided around that specific area of need and carefully examine the wording of the relevant DST levels to cross-match the information and see if this provides further clarity. Additional evidence may be sought, although this should not prolong the process unduly. If this does not resolve the situation, the disagreement about the level should be recorded on the DST along with the reasons for choosing each level and by which practitioner. This information should also be summarised within the recommendation so that the CCG can note this when verifying recommendations.'*

In our opinion someone with tetraplegia and intact skin should score at least a 'High' score for 'Mobility' and 'Continence' domains and 'Moderate' for Skin domain. For the autonomic dysreflexia element of 'Other Significant Care Needs' you should expect a 'Severe' need score. Scores for the Breathing domain are influenced by your level of injury and presence/absence of e.g. sleep apnoea, whilst that for Drug Therapies & Medication (including Symptom Control) depends on pain levels, and possibly the frequency with which you experience autonomic dysreflexia. It is important to stress the risks associated with Autonomic Dysreflexia, even if it has been some time since your last episode. An attack can occur even where there is no history of previous episodes.

Irrespective of how the assessors score your needs, you should make them aware that you know that your needs and disability are similar to/worse than those of Ms Coughlan (Appendix 1), and that they

**Para 157 – National Framework**

*“CCGs should be aware of cases that have indicated circumstances in which eligibility for NHS Continuing Healthcare should have been determined, and where such an outcome would be expected if the same facts were considered in an assessment for NHS Continuing Healthcare under the National Framework (e.g. Coughlan (refer to Annex B) or those cases in the Health Service Ombudsman’s report<sup>1</sup> on NHS funding for the long-term care of older and disabled people “*

Once the multidisciplinary team has reached agreement, it should make a recommendation to the CCG on eligibility. Assessors making a recommendation of eligibility/ineligibility for Continuing Healthcare, and those adjudicating on the final decision are viewing your care needs in terms of their **Nature, Complexity, Intensity** (continuity of care) and **Unpredictability**. If assessors say your needs are routine, it is up to you to point out how unpredictable and complex they are, and how they interact.

To help you to make this point and give evidence to your arguments SIA has, in conjunction with the British Association of Spinal Cord Injury Specialists (BASCIS) and the Multidisciplinary Association of Spinal Cord Injury Professionals (MASCIP) produced a Statement on Tetraplegia and Autonomic Dysreflexia in respect of NHS continuing Healthcare. This is available from the Advocacy Team.

Remember: Only in exceptional circumstances, and for clearly articulated reasons, should the multidisciplinary team’s recommendation not be followed by the CCG.

You are entitled to give input to the assessment and to receive a copy of the completed form. Request a copy **before** it goes to the adjudicating Panel/CCG to check for accuracy, citing

**Para 159 of the National Framework**

*‘Once the eligibility decision is made by the CCG, the individual should be informed in writing as soon as possible (although this could be preceded by verbal confirmation where appropriate). This written confirmation should include:*

- *the decision on primary health need, and therefore whether or not the individual is eligible for NHS Continuing Healthcare;*
- *the reasons for the decision;*
- *a copy of the completed DST;*
- *details of who to contact if they wish to seek further clarification; and*
- *how to request a review of the eligibility decision’*

Finally, keep copies of all documents used to support your assessment and any correspondence from the CCG safely in case you need to refer to them again. Even if you are deemed eligible for NHS Continuing Healthcare, your eligibility will be reviewed regularly thereafter (at least annually and when receiving NHS Continuing Healthcare for the first time, after three months).

SIA has seen increasingly a tendency for CCGs to declare people with SCI who were eligible subsequently ineligible after a review, despite there being no evidence of clinical improvement

or change in need to warrant this. It is considered that such decisions are budget driven and not needs driven. If that happens to you, contact SIA's Advocacy Department about how to mount an appeal against the decision.

## 7.0 APPEALING A DECISION

You should only accept a decision from the CCG in writing, and this should include an explanation of the basis for the decision. Should you be turned down when you first attempt to secure NHS Continuing Healthcare (or at a subsequent review) you should receive a detailed rationale for the decision

The reasons given for a decision on eligibility should **not** be based on:

- the person's diagnosis;
- the setting of care;
- the ability of the care provider to manage care;
- the use (or not) of NHS-employed staff to provide care;
- the need for/presence of 'specialist staff' in care delivery;
- the fact that a need is well managed;
- the existence of other NHS-funded care; or any other input-related (rather than needs-related) rationale.

If you are turned down for NHS Continuing Healthcare funding you have a right to appeal against the decision. The grounds on which you can lodge an appeal are:

- a) The procedure followed in reaching the decision as to your eligibility for NHS Continuing Healthcare. This can include factors such as:
  - Whether your assessment was conducted by a properly constituted Multidisciplinary Team;
  - Whether the multidisciplinary team properly considered your care needs in each domain;
  - Whether the decision-making panel did not follow the recommendation of the multidisciplinary team without justification;
  - etc
- b) The decision regarding your eligibility for NHS continuing Healthcare. This can include factors such as:
  - Whether the decision is lawful when considered against existing ombudsman/court decisions such as the Coughlan Judgement

There are three stages involved in appealing against a decision

### ***Stage 1: Local Review***

The decision is reviewed locally by the CCG. This is usually done by setting up a second panel which looks again at the assessment and decision. You should be permitted to submit written reasons as to why you disagree with the original decision and additional evidence to support your reasoning. You do not however have an automatic right to attend the local review panel meeting in person, although some CCG's do allow this.

The timescales for local reviews laid down by the Department of Health are:

- a) You have 6 months from the date of the original decision letter in which to ask for a review of that decision;
- b) The CCG must complete their review of the original decision within 3 months of the date on which you lodge your appeal.

## ***Stage 2: Independent Review***

The decision taken at the Local Review stage is further reviewed by the NHS Commissioning Board (this is the body that oversees the activities of CCG's). This is usually done by setting up an independent review panel which looks again at the decision taken by the CCG. Once again you should be permitted to submit written reasons as to why you disagree with the CCG's decision and additional evidence to support your reasoning. You should also be permitted to attend the independent review and make your submissions in person.

The timescales for independent reviews laid down by the Department of Health are:

- a) You have 6 months from the date of the local review decision in which to ask for an independent review;
- b) the NHS board must complete the independent review of the decision within 3 months of the date on which you lodge your appeal.

## ***Stage 3: The Parliamentary and Health Services Ombudsman***

If you are unsuccessful at both the local and independent review stages you can appeal to The Parliamentary and Health Services Ombudsman and ask him to review the decision. You have 12 months from the date of the independent review decision in which to refer your case to the Ombudsman.

Only once you have exhausted all three stages of the appeals process will you be permitted to make a legal challenge against the decision through the courts.

Remember that assessments have to be carried out by a trained Multi-Disciplinary Team (a team of at least two professionals, usually from both the health and the social care disciplines). It should include those who have an up-to-date knowledge of the individual's needs, potential and aspirations, but in reality may not. If the assessment is carried out by a single individual and you are turned down, this is grounds for appeal.

The SIA's Advocacy Team can provide guidance on writing letters of appeal, and help you identify the grounds for appeal. We may advise you to use the services of one of several firms of solicitors specialising in this work. You will need a copy of the original DST assessment form and any supporting documentation to base your appeal on. You can apply for access to your medical records if you need to, and if you encounter problems with this you can submit a request under the Freedom of Information Act (2000).

## Appendix 1:

### Summary of Key Court/Ombudsman Cases in which NHS Continuing Healthcare has been awarded

The following case summaries have been adapted from guidance issued by the Association of Directors of Adult Social Services and the Local Government Association. ADASS and the LGA recognise the difficulties in extrapolating from the limited information publicly available on those cases that have been decided in the court or adjudicated by the Health Service Ombudsman. However, they state that these cases give clear indication of where the correct line between LA and NHS responsibility lies in those particular circumstances. ADASS and LGA advise that where an individual has genuinely similar needs to those outlined in these cases then the same eligibility decision (for NHS CHC) should be the outcome of the assessment. *This will be the case irrespective of the outcome of the DST assessment, although the expectation is that the correct application of the Framework and DST should confirm their eligibility.* The first case is especially pertinent because it involves Pamela Coughlan, whom has a tetraplegic lesion, and it is on her case that much of current NHS guidance on Continuing Healthcare is predicated.

#### ***Pamela Coughlan - a C5/6 (complete) tetraplegic lesion – Pen Picture of Clinical, Nursing and Care needs***

Pamela Coughlan was injured in a road traffic accident in 1971 and as a result became spinal injured and wheelchair dependent. She retained some (very limited) use of her hands with which she could manoeuvre her electric wheelchair and write (with a pen strapped to her hand). She remained completely mentally aware, could access the Internet, converse freely and represent her views articulately. She had no cognitive impairment or behaviour that could be described as challenging.

Pamela Coughlan was paralysed in the lower part of her body, with no movement in her legs, and limited movement in her upper torso. She required hoisting for all transfers however once transferred into a wheelchair she has a reasonable amount of independence. She required repositioning approximately 8 times per day to maintain skin integrity. She did not require a regular programme of active or passive physiotherapy or exercise, although being assisted to stand twice per week assisted with maintaining appropriate organ positions and strengthening her bones.

She wore a corset during the daytime to keep her chest upright without which she would have had breathing difficulties. There were no night care issues regarding her breathing.

She was doubly incontinent; needing intermittent catheterisation, every 3 hours as this proved the most effective way of keeping dry. She required manual evacuation of her bowels every second night.

Because of her injury she was unable to maintain her core body temperature, which was unstable and variable, and consequentially, because of excessive perspiration, she required changes of clothes and the corset up to three times a day. Pamela was able to tell when she

was too hot or too cold and therefore proactive monitoring was not required regarding this aspect of her care.

Pamela Coughlan was dependent on others for all aspects of her personal care and daily living activities. She could eat independently using a spoon strapped to her hand provided that the food is cut up for her. Someone needed to hold a cup whilst she was drinking as her hand would spasm if she touched a hot cup.

Clinically and from a nursing perspective she was stable with predictable needs some of which presented with medium risks e.g. regarding fainting if air flow was inhibited (managed by corset), spasm provoked by heat (e.g. hot cup), autonomic dysreflexia (very high blood pressure) as a result of pain or injury below the spinal injury site (C5/C6).

All of her medication was routinely prescribed and administered by mouth; Senokot, Docusate, calcium, Irin. Once her condition stabilised she did not require an allocated consultant nor require any interventions from 'specialist' healthcare professionals.

The court found that Pamela Coughlan's needs "were primarily health needs for which the Health Authority is, as a matter of law, responsible".

Pamela Coughlan's healthcare needs and her need for registered nurse care were neither complex nor unpredictable. However the court took the view that a) the quality and quantity (nature and intensity) of her health needs and interventions were such that she had predominantly healthcare needs and b) her need for registered or unregistered nurse care was more than incidental or ancillary to her accommodation needs and was not of a nature that a Local Authority could reasonably provide (i.e. they were not social care needs).

### ***Mrs N - Wigan and Bolton Ombudsman Case***

Mrs N, had a history of strokes, as a result of which she had no speech or comprehension. She was unable to swallow and required feeding by a PEG tube. She was cared for in a nursing home. She had poor sitting balance and was nursed mainly in bed. She was unable to weight bear.

Mrs N was incontinent and had a catheter in place. She required assistance with her bowels every 3 to 4 days. Her skin required monitoring and she needed assistance with all care. She tolerated the feeding regime well and the PEG presented no problems. She was generally very pleasant and often smiling. She did not appear to have any insight or recognise people around her.

The Health Services Commissioner found that:

"It is clear from the information I have seen about Mrs N's condition that she was extremely dependent and required a high level of physical care; like Miss Coughlan she was almost completely immobile; and she was doubly incontinent. I have seen no evidence that she had breathing difficulties as Miss Coughlan had; but she required PEG feeding which Miss Coughlan did not. She was unable to communicate verbally. I cannot see that any authority



could reasonably conclude that her need for nursing care was merely incidental or ancillary to the provision of her accommodation or of a nature one could expect social services to provide. It seems clear to me that she, like Miss Coughlan, needed services of a wholly different kind. If the Health Authority had had a reasonable policy and applied it appropriately, they would have provided NHS care for Mrs N”.

### ***F3 Malcolm Pointon – Ombudsman Case***

Mr Pointon was 63 at the time of the Ombudsman judgement. He had Alzheimer’s disease. He was doubly incontinent, was unable to feed himself, could not speak, could not understand instructions, had poor visual perception, needed constant supervision as he was a risk to himself, needed frequent reassurance and needed assistance with all aspects of personal care

The Ombudsman found that DH guidance had not been properly followed was the assessment tools used were focussed on physical care and not psychological needs. Mrs Pointon was giving highly personalised care with a high level of skill. This nursing care was equal to, if not superior than, that which Mr Pointon would have received on a dementia ward. The report criticises the belief that nursing care can only be provided by qualified nurses.

The Ombudsman found that “the PCT assessed Mr Pointon against the wrong criteria, once again focusing on physical needs and also failing to recognise that the standard of care provided by Mrs Pointon was equal to that a nurse could provide. I uphold the complaint.”

The Ombudsman also recommended that the PCT consider whether any retrospective payments should be made to Mr Pointon.

**Source:** Commentary and Advice for Local Authorities on The National framework for NHS Continuing Healthcare and NHS-funded Nursing Care association of Directors of Adult Social Services (ADASS) and the Local government Association (LGA) October 2007

## **Appendix 2:**

### **References**

1. National Framework for NHS Continuing Healthcare And NHS Funded Nursing Care 2012
2. NHS Continuing Healthcare Checklist
3. Decision Support Tool For NHS Continuing Healthcare
4. R v. North and East Devon health authority ex p Coughlan (1999)
5. R (on the application of Grogan) v Bexley NHS Care Trust [2006]

### **Disclaimer**

SIA has checked with sources believed to be reliable in their efforts to provide information that is accurate, comprehensive, and timely at the date of publication. However, human error and changes can and will occur. The Spinal Injuries Association expressly disclaims any representation or warranty, expressed or implied, concerning the accuracy, comprehensiveness, or suitability of the information for a particular purpose. SIA has produced this document in good faith and is not responsible for any errors, omissions, or results obtained from the use of the information herein.

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Monday to Friday

9.30 am – 1.00 pm and  
2.00 pm – 4.30 pm