

Continuing Healthcare

Information pack (revised April 2013)

...because life needn't stop when you're paralysed

Produced by
***sia* ACADEMY**



CONTENTS

	Page
1. Introduction	3
2. NHS Continuing Healthcare	4
3. The Assessment and Decision-Making Process	6
4. Care Commissioning	14
5. The Pros and Cons of NHS Continuing Healthcare	15
6. Preparing for Your Assessment	17
7. Appealing Decisions	36

APPENDICES

1. Summary of Key Court/Ombudsman Cases
2. References

1.0 INTRODUCTION

This information booklet has been updated following the revision by the NHS of '*The National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care*' in 2012 to reflect changes in NHS structures created by the Health and Social Care Act 2012. It supersedes the Continuing Healthcare Information Pack issued by the SIA Academy in 2010.

The revised framework came into effect on November 28 2012 for PCTs, but will be implemented by their successor bodies, Clinical Commissioning Groups (CCGs) on 1st April 2013 in England . The framework does not apply in Scotland, Wales or Northern Ireland. It contains some important clarification of eligibility criteria and practice guidance.

| 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 (2012) 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. Deciding whether this is the case involves looking at the totality of the relevant needs. Where an individual has a primary health need and is therefore eligible for NHS continuing healthcare, the NHS is responsible for providing all of that individual’s assessed health and social care needs – including accommodation, if that is part of the overall need” (National Framework 2012; Para 33)

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 are 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’. This capital limit is under review by the Government and is anticipated to rise at an as yet unannounced date.

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 person should be

considered to have a primary health need when the nursing or other health services they require, when considered in their totality, are:

- (a) where that person is, or is to be, accommodated in a care home, more than incidental or ancillary to the provision of accommodation which a social services authority is, or would be but for a person's means, under a duty to provide; or*
- (b) of a nature beyond which a social services authority whose primary responsibility is to provide social services could be expected to provide '.*

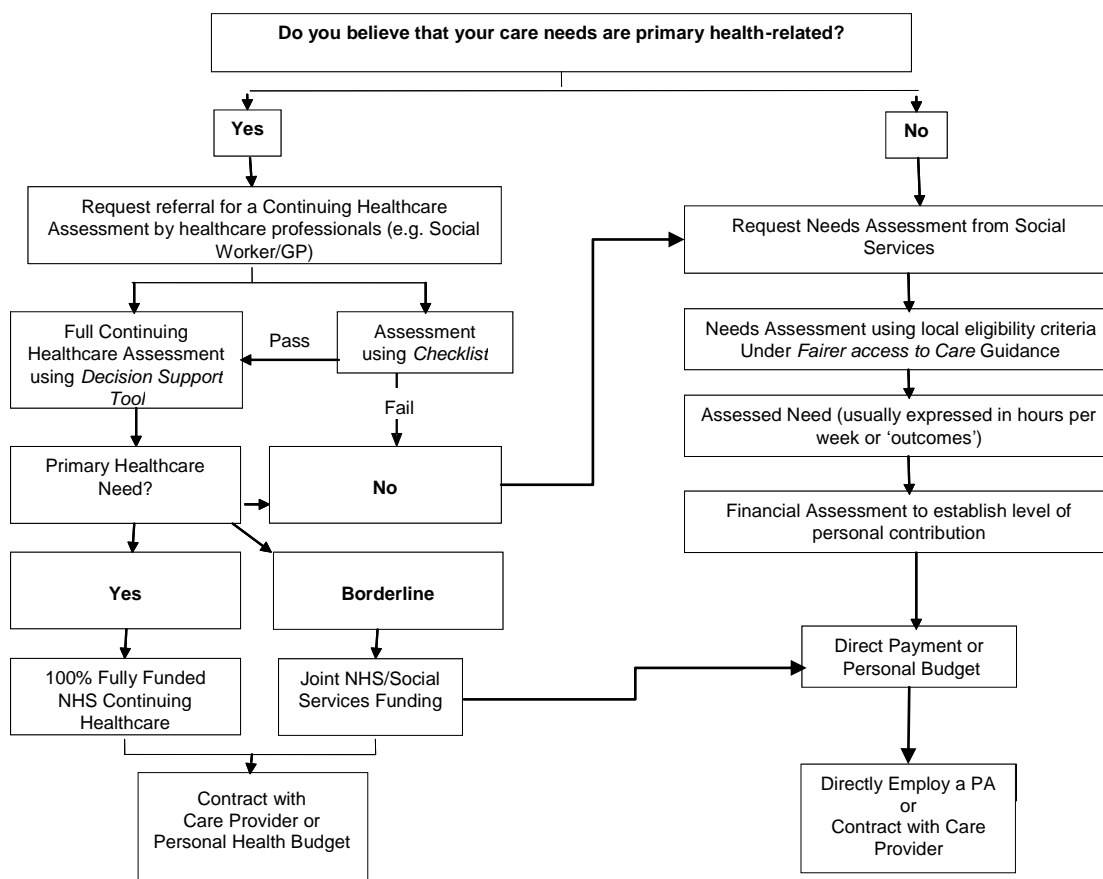
The Local Authority (LA) can only meet nursing/healthcare needs when, taken as a whole, the nursing or other health services required by the individual are below this level. If the individual's nursing/healthcare needs, when taken in their totality, are beyond the lawful power of the LA to meet, then they have a 'primary health need'. (Source: National Framework 2012 PG3.4).

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 113-117). 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. **Behaviour** assesses the level of challenging behaviour

2. **Cognition** refers to individuals with a learning disability, an acquired or degenerative condition which places them at risk of self harm, neglect or exploitation
3. **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
4. **Communication** needs relate to expression and understanding, not with the interpretation of language.
5. **Mobility** considers the needs of individuals with impaired mobility.
6. **Nutrition (food & drink)** considers issues such as malnutrition, dehydration and aspiration.
7. **Continence** considers level of need for both bladder and bowel management
8. **Skin (including tissue viability)** looks at any condition that has the potential to affect the integrity of the skin.
9. **Breathing** needs relates to the effects of breathlessness, and requirements for supportive therapy such as oxygen, CPAP or tracheotomy.
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

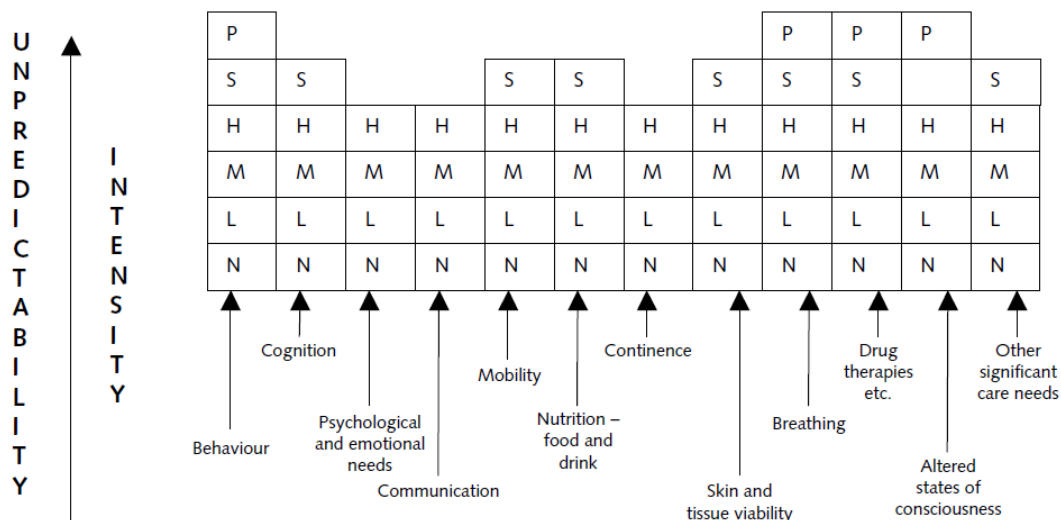
The second stage is the full assessment that will determine whether a recommendation of eligibility or ineligibility for NHS Continuing Healthcare is made. This stage is much more rigorous and must be carried out by an appropriately qualified Multi-Disciplinary Team (MDT) using what is known as the 'Decision 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
- L - Low
- M - Medium
- 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 and Practice Guidance ([link](#)), the Checklist ([link](#)) and the Decision Support Tool ([link](#)), 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." (Decision Support Tool for NHS Continuing Healthcare, Summary (vii))

"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 [MDTPCT](#) 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)
- if rationale not clear can refer back to MDT.

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. 90).

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.

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. 90) 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. There is now another option called a Personal Health Budget (PHB) which allows you to retain a greater say in who provides your care. Direct Payments (DPs) of NHS Continuing Healthcare funding, which allow you to directly employ your own carer(s) are one of the ways, but PHBs can also be held by a third party on your behalf. Currently, Direct Payments of PHBs are available in selected areas, but the Government has announced that all people receiving NHS Continuing Healthcare will have a right to ask for this option by 2014. 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 CCG's 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.

However it may not be possible to use NHS Continuing Healthcare to employ your own PA's. This is primarily because at present CCG's don't have the legal powers to offer CHC as a Direct Payment. The government is in the process of changing the law and from April 2014 everyone eligible for CHC funding will be entitled to ask for a Personal Health Budget (PHB) in the form of a Direct Payment. Sometimes the NHS will resist you employing your own PA's because they want to assure themselves that you are not exposed to risks or lack of continuity of care. The fact that the NHS does not have a culture of empowering patients for the most part is due to the newness of Personal Health Budgets.

If you have been employing PA's up to this point (either with LA funding or self-funding), you may view this as an unacceptable loss of control.

If you wish to retain your existing directly employed care team you may be able to do this. Options for doing this include transferring their employment (under TUPE regulations) to a care provider to provide care solely to you or exploring whether your CCG is in a position to offer you a PHB . You should seek advice for these options.

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 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 CCGPCT than being cared for at home; unless this accords with your wishes, you should resist this forcefully and seek advice from SIA's Advice Line.

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

"Needs should not be marginalised because they are successfully managed. Well-managed needs are still needs. Only where the successful management of a healthcare need has permanently reduced or removed an on-going need will this have a bearing on NHS continuing healthcare eligibility. However, there are different ways of reflecting this principle when completing the DST. For example, where psychological or similar interventions are successfully addressing behavioural issues, consideration should be given as to the present-day need if that support were withdrawn or no longer available and this should be reflected in the Behaviour domain". (Paragraph 28, Decision Support Tool For NHS Continuing Healthcare)

Assessors are further instructed that: *"It is not intended, however, that this 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 needs are being managed via medication (whether for behaviour or for physical health needs), it may be more appropriate to reflect this in the Drug Therapies and Medication domain. Similarly, 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". (Paragraph 29, Decision Support Tool for NHS Continuing Healthcare)

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.

1. Behaviour

This domain relates to challenging behaviour (e.g. aggression, extreme frustration with communication difficulties) that poses a predictable risk to self or others. For most members, behaviour is not likely to score very highly; however some members may have acquired a brain injury as a part of becoming 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 they may experience suicidal ideation. Any behaviours such as these 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.

2. Cognition

This may apply, but is not limited to, individuals with learning disability and/or acquired brain injury (ABI) and degenerative disorders which places them at risk of self-harm (including deterioration of health), neglect or exploitation. This domain also refers to such things as regular short-term memory loss, disorientation, and periods of confusion. Occasional difficulty with memory and decisions/choices requiring support or assistance should achieve a low score.

Higher scores may be achieved by demonstrating instances of limited ability to assess basic risks, difficulty in making your own decisions/choices, even with prompting and supervision (e.g. during an episode of autonomic dysreflexia or if unwell due to high temperature as a result of UTI or chest infection). Severe cognitive impairment may include, lacking short-term memory, problems with long term memory or severe disorientation or being unable to assess basic risks, and being dependent on others to anticipate even basic needs to protect you from harm (e.g. water temperature when bathing).

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

3. Psychological/Emotional

Mood disturbance or anxiety symptoms (e.g. due to problems with your PA or in getting and arranging care) or periods of emotional distress arising from the frustration of your physical limitations that have an impact on your health and/or wellbeing are relevant here. Factors to consider include withdrawal from attempts to engage in support, care planning and daily activities, social isolation arising from reluctance/inability to go out, to meet people, to involve yourself with friends and family, or being self-conscious about yourself, your appearance or your SCI disability. Any of these factors can be considered as demonstrating a need associated with this domain.

Whilst most members will only score 'Low' or 'Moderate' in this domain, for some the pressures of coming to terms with and living with a SCI can and do create severe problems (including suicidal ideation) that require medical intervention or counselling and justify a 'Moderate' or 'High' care need score. If you are taking medication such as anti-depressants to treat depression, or drugs to control stress, mood swings, etc., these should be mentioned here (and also in Drug Therapies domain, below). If you experience high levels of pain that affect your psychological well-being, this should be stressed (note interaction here with Drugs & Medications domain).

Of course, if you already have an established and adequate social care package, you may well be able to participate actively in society and not be socially isolated or have psychological issues. This would be an example of a 'well-managed need', which is dependent on you maintaining the same level of support under Continuing Healthcare, and the likely impact if that were removed that should be recognised.

4. Communication

Most members would not normally have major communication problems, although many, especially those whose control of their breathing is limited, for instance having had a tracheotomy, may find conversation more difficult. Perhaps of more significance here is the inability to talk loudly, or shout, which could pose a risk if you need to summon help quickly. You may need assistance to use/hold a telephone (e.g. to put on a headset) or to use your computer. Your dependence on an environmental control system (e.g. POSSUM) should be recorded (e.g. how do you let carers/visitors/health professionals into your house when you are in bed or summon your PA?). If you have a problem with short-term memory, the inability of tetraplegics, for example, to 'jot' things down (as an able-bodied person would) is relevant and interacts with the 'Cognition' domain. If you use any other communication aids such as hearing aids and need assistance with fitting them this should be mentioned.

If you have Obstructive Sleep Apnoea treated with a CPAP, particularly if using a full-face mask, you may find it difficult to speak/communicate when using it. Finally, you may not be able to communicate or express your needs properly during episodes of autonomic dysreflexia or if suffering from a high temperature occasioned by UTI or chest infection or if you become hypothermic or hyperthermic due to your body's impaired temperature control (poikilothermia).

Accordingly, your carer or PA may need to anticipate your needs in line with the criteria for a 'Moderate' needs score:

'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'.

Attempts to score you as 'No needs' should therefore be resisted.

5. Mobility

There will be a temptation for assessors looking at you in a wheelchair or bed to score your mobility need as 'Moderate' based on the following criterion:

In one position (bed or chair) for the majority of time but is able to cooperate and assist carers or care workers.

However, this should be rejected as tetraplegic wheelchair-users should be able to demonstrate a 'High' level of need in this key domain, as demonstrated by at least one of the following criteria:

Completely unable to weight bear and is unable to assist or cooperate with transfers and/or repositioning.

OR

Due to risk of physical harm or loss of muscle tone or pain on movement needs careful positioning and is unable to cooperate.

OR

At a high risk of falls (as evidenced in a falls history and risk assessment).

OR

Involuntary spasms or contractures placing the individual or others at risk

Identifying a 'High' level of need should be an achievable score, but there may be strong grounds for fulfilling a 'Severe' score which is described as:

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.

Your justification for this could be based on:

- the elevated risk of fragility fractures associated with long-term wheelchair use,
- the critical role positioning plays in
 - maintaining skin integrity,
 - avoiding long-term postural asymmetries (e.g. scoliosis or windswept hips)
 - maintaining breathing,
 - managing pain or involuntary muscle spasm issues, particularly for those with tracheotomy and/or high levels of tetraplegia

Things to draw to the attention of the assessors are:

You are **paralysed** and confined to a wheelchair/bed during the day and bed at other times, and are unable to walk or weight bear (if applicable). If you need an electric/powered assistance wheelchair or require a care-giver to push your wheelchair to move around indoors and/or outdoors, make sure you stress that during the assessment. How do you control your wheelchair (e.g. chin-operated control, adapted steering knob)?

Point out your lack of trunk muscles, that you cannot support yourself, and easily overbalance. If you use a lap strap to secure yourself in your chair to prevent you falling out make sure you are wearing it during the assessment.

Do you suffer from involuntary muscle spasms (spasticity/muscular hypertonicity; <http://www.spinalcord.uab.edu/show.asp?durki=46905>) that could throw you out of the chair or unbalance you or alter your posture? If you use Baclofen or other prescribed muscle relaxant drugs, say so. Is it effective?

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 be explained. How many people are needed to transfer you (moving and handling issues)? How many times a day? As a minimum you will need to be hoisted/transferred twice a day; however, if bladder/bowel accidents occur or you need bed-rest or become unwell during the day the frequency will increase and is not predictable. Have you ever suffered injuries as a consequence of not being transferred properly?

It is essential to be correctly transferred and positioned in both wheelchair and bed to minimise complications. These can include: ischial/sacral skin breakdown leading to decubitus ulcer (pressure sore) if shearing forces are applied to skin during transfers or if sitting in a misaligned/slumped posture or with creased clothing; kinking or pulling of your catheter tubing which is liable to cause autonomic dysreflexia; falling from the wheelchair due to loss of balance if not correctly positioned; discomfort/pain.

For older SCI lesions in particular, there is also a significant risk of fragility fractures arising (due to osteoporotic weakening of bones) if you are moved inappropriately by inadequately/untrained care-givers. Longer term, chronic musculoskeletal abnormalities (e.g. scoliosis, lordosis, pelvic obliquity, windswept hip) can ensue causing pain, deformity and thereby increased risk of pressure ulcer. Sustained poor positioning in your wheelchair can give rise to contractures of hips, knees and ankles, resulting in loss of range of movement, further disability and increased risk of pressure ulcers.

Explain about positioning in bed (e.g. you require the assistance of trained carer(s) for all bed mobility and re-positioning, currently being turned (number of times?) through the night). Stress how this can be unpredictable (e.g. if you have an incontinence 'accident' or sweat profusely) and increases if you develop a skin problem, or a urinary tract infection, cold, chest infection etc when skin tolerance would decrease. If confined to bed for extended periods, you would require turning more frequently, day and night). Do you use any equipment to position you in bed, such as a sliding sheet? Do you need to have pillows positioned to ensure pressure sores do not develop?

Note interaction here with 'Skin' domain.

Emphasise about positioning requirements in your wheelchair (e.g. if you require the assistance of trained carer(s) and a slide sheet for positioning in the wheelchair), and how optimum posture and positioning when seated in wheelchair is imperative in order to reduce postural asymmetries and long term postural complications. Also if you have a moulded chair back or high neck support, bring this to the assessors' attention and explain why it is necessary. Explain how re-positioning has to be done several times a day if you get unpredictable muscle spasms which induce involuntary postural changes or just to remain comfortable or to ensure pressure relief to skin.

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 and as part of the management for spastic hypotonia you may have a standing programme using a standing frame/ standing chair/tilt table of up to minutes times a week. Other reported benefits of regular standing include improving digestion and circulation, and a reduction in the incidence of urinary tract infection. You probably require supervision from a trained carer for the duration of standing due to a risk of postural hypotension and potential autonomic dysreflexia episodes (both of which would require immediate intervention), as well as assistance to use the equipment.

Additionally, you are at risk of losing 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.

Note: passive exercises and a standing programme are also relevant to 'symptom control' in the Drug Therapies & Medication: Symptom Control domain (below).

Many people with SCI need to rest on the bed during the day to relieve pain and/or skin pressure from prolonged sitting. If you -do this, explain how and why this is necessary. Explain why it is necessary to get regular pressure relief during the time you both are in the wheelchair and in bed and that you need assistance to do this.

Note: because of your immobility, the Mobility care needs interact with the Skin care needs, and assessors should acknowledge this interaction in both domains (permissible so long as they note this on the DST).

Point out that as part of your condition you have hypotonia (lost muscle tone) in your lower limbs due to complete paralysis. Explain what this means in terms of your vulnerability to pressure sores and your inability to generate heat through your large muscles in your lower limbs, rendering you vulnerable to developing hypothermia.

If you suffer from oedema (fluid retention) in your feet, ankles and calves, point this out. If you wear surgical (elasticised) 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.

6. Nutrition

The definitions of needs in this domain are particularly challenging and do not readily allow people with SCI, even high lesion tetraplegics, to score highly. Members who require P.E.G feeding are likely to obtain a 'High' score only if PEG is problematic, but for most members who can feed themselves the score is likely to be 'Low'. Argue for at least a 'Moderate' score if you are a tetraplegic who requires a care-giver to feed you, based on:

Needs feeding to ensure adequate intake of food and takes a long time (half an hour or more), including liquidised feed.

If not scored as such, refer assessors to comparison with the nutrition needs of Ms Coughlan who is eligible for NHS Continuing Healthcare (Appendix 1). She can eat independently using a spoon strapped to her hand provided that the food is cut up for her, although someone needs to hold a cup whilst she is drinking. Ensure that the MDT understands that food has to be prepared for you and cut up (if applicable). Can you hold a cup? Do you need to be fed? What if you are confined to bed?

You should point out the importance of regular and copious fluid intake (2.5 – 4 litres daily) in order to reduce the risk of urinary tract infections/catheter blockages and avoid constipation. How is fluid delivered to you when you are in bed?

Note: interaction with 'Continence' domain, i.e. because of high fluid intake; you need your urine drainage bag emptied frequently.

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

A problem you may have is with choking on food, which because of the paralysis of respiratory muscles you can't clear with a cough. Need for 'skilled intervention' by a care-giver to provide 'assisted coughing'.

Note: *interaction with ‘Breathing’ domain makes it possible to argue for a higher need score.*

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 e.g. difficulty in assessing skin integrity, pre-disposition to obstructive sleep apnoea (breathing), difficulty in transferring, moving and handling (mobility) or catheter change (Continence). Conversely, inadequate/poor nutrition and/or inability to maintain sufficient weight 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).

Note: *interaction with skin, breathing, mobility and ‘other significant needs’ domains.*

7. Continence

This is a key domain, but crucially there is no ‘severe’ score; moreover, the complexity and unpredictability of SCI continence needs are often poorly understood by assessors.

A "high" level of need in this domain is described as:

“continence care is problematic and requires timely and skilled intervention, beyond routine care (for example frequent bladder wash outs, manual evacuations, frequent re-catheterisation)”,

it would be expected that most, if not all, tetraplegics would score ‘High’ in this domain. However, assessors have sometimes argued that a well-managed bowel routine and use of a penile sheath or indwelling catheter for urine drainage will only score ‘Moderate’, which is described as:

“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”.

It is therefore vital that you point out all the complications and risks associated with your continence care, the skills needed in that care, and that a well managed need is still a need! You should also draw to their attention to the continence needs of Ms Coughlan (Appendix 1), whose needs, although well managed are nevertheless ‘primarily health care needs’.

If you require digital rectal stimulation and/or digital removal of faeces (‘manual evacuation’) and/or autonomic dysreflexia (AD) is a factor in your continence care, these factors are primarily what makes your continence care “problematic” and “beyond routine care”. Continence issues are the most common causes of AD. Autonomic dysreflexia is a condition unique to someone with a SCI above the level of T6. Make sure that the assessors understand that such an attack is a **medical emergency** and, if unresolved, could lead to a fatal cerebral haemorrhage. It has to be dealt with immediately and appropriately, and requires skill, training and knowledge on the part of those caring for you which go beyond that which would be

otherwise needed to fulfil your continence needs. Even if you have not suffered an episode recently or can normally recognise and react (with assistance) to symptoms (because your continence needs are well-managed), a major attack can be triggered at anytime.

Note: autonomic dysreflexia per se should be dealt with under 'Other significant care needs', domain 12, and a copy of SIA's Factsheet explaining AD, should be given to the assessors. Assessors should score you for AD in domain 12, but in the Continence domain they 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' domain due to skin-faeces contact.

Draw attention to the fact that you need "skilled intervention" with bowel evacuation as part of your bowel care. Typically, this will involve digital rectal stimulation (DRS) and digital rectal evacuation ('manual evacuation') of faeces from the neurogenic bowel, often with use of a chemical stimulant (e.g. bisacodyl suppositories/rectal liquid, sodium docusate) enema, administered by a skilled care-giver/district nurse on a daily/alternate-day basis. Alternatively, you may use the 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 care-giver/district nurse 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 autonomic dysreflexia. Explain the complications that can occur as a result of the way your bowel care is managed (i.e. regular digital interventions, use of enemas), including such things as rectal prolapse or haemorrhoids (piles) and how these complicate its management.

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

Bladder care: Describe your bladder care (e.g. intermittent catheterisation/penile sheath/indwelling urethral or supra-pubic catheter/urostomy). If catheterised, your need for frequent (e.g. monthly/6-weekly) and sometimes unpredictable re-catheterisation or bladder washouts are health needs requiring "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. 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 round 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.

8. Skin (including tissue viability)

Another key domain for SCI, but one in which the criteria for a 'Severe' score (which would be likely to ensure eligibility) 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 SCI have a lifetime risk of up to 80%, and an annual incidence of 30%, of 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 the fact that it 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

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, e.g. 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 (e.g. pillows) used to help reduce skin pressure. Mention any special seating equipment that you require, e.g. 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/index.htm>).

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. Cetraben) 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...' and 'Continence' domains.*

9. Breathing

You need to point out to assessors that tetraplegia and higher paraplegic lesions involve paralysis of respiratory muscles. Even at T4 level paraplegics are unable to use two thirds of their intercostal muscles; (the muscles between the ribs which in respiratory terms are second only to the diaphragm in importance.) You are also unable to use your abdominal muscles which are important in helping you to cough. For tetraplegics, point out that as your breathing is diaphragmatic (driven solely by your diaphragm), it is shallow and you lack the ability to cough to clear your airways, chest or if you choke.

Note: *interaction with 'Nutrition' domain in which choking risk is assessed.*

You are therefore at risk of developing chest infections following your injury. When a chest infection or cold develops, you will probably require assistance to clear secretions. This will include repositioning, manual techniques and an assisted cough. Care-givers will need to be

trained to identify signs and symptoms and treat appropriately. Carer-assisted coughing is a recognised and skilled technique to help you cough. Your vulnerability to influenza and chest infections leading to pneumonia should be emphasised, and you should be immunized against these risks. You should argue for a 'moderate' score for this domain if you have shortness of breath that affects your activities of daily living.

You may suffer from obstructive sleep apnoea (OSA), in which 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.

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. Make sure your assessors cross-reference this problem with the '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.

10. Drug therapies and medication: Symptom control

Scoring in this domain depends on (i) medication usage, (ii) pain intensity you experience, (iii) on 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 Ms Coughlan (Appendix 1) 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, 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, as well as in the 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. If you are diabetic you may be controlling this with insulin and need regular injections. You may take Baclofen to control involuntary muscle spasms or have a Baclofen pump fitted. Don't forget complementary medicines (e. g. 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 or antibiotic prophylaxis for UTI with 'Continence').

As a potential/actual sufferer of autonomic dysreflexia (AD) you should have a vasodilator, e.g. Glyceryl trinitrate (GTN) as a sub-lingual spray or nifedipine always available in case of an attack (see also domain 12). Administration and monitoring (e.g. blood pressure) of these drug regimens and the ongoing management of the condition require a nurse or trained carer to be knowledgeable, skilled and trained. The potential risks to your well-being associated with AD should warrant a 'High' score, which is described as:

"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".

If even with such monitoring the condition, AD, is *usually problematic to manage*, however, this should support a 'Severe' score. Examples of this might be if a catheter has to be changed or an emergency intermittent catheterisation needs to be performed to alleviate the AD. Similar considerations apply if you require insulin injections to counter hypoglycaemia.

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.

11. Altered states of consciousness

Few tetraplegics tend to score anything other than 'low' or 'no needs' here. The normal state of consciousness comprises either the state of wakefulness, awareness, or alertness in which most human beings function while not asleep. If you experience autonomic dysreflexia, however, it is probable that during an episode you have reduced awareness and alertness and experience '*Clouding of consciousness*', which is a very mild form of altered mental status in which the 'patient' has inattention and reduced wakefulness. It may therefore be possible to argue for a 'Moderate' need score, based on there being:

Occasional episodes of ASC that require the supervision of a carer or care worker to minimise the risk of harm.

Most tetraplegics have low blood pressure and, for some, changes in position, such as getting up from a lying position in bed to sitting upright in your wheelchair may lower this further causing postural hypotension (see domain 12). As a result you may experience a period of light-headedness, dizziness or even fainting. You should have this recorded and tell the assessor what actions your care-giver needs to take when this happens, such as tipping you back in your wheelchair for a short period to raise your blood pressure.

Anyone who suffers from epilepsy, even if under control and there have been no recent episodes, should mention this to the assessor.

12. Any other significant needs

The National Framework (para 86) states that "*In certain cases, an individual may have particular needs that are not easily categorised by the care domains described here. In such circumstances, it is the responsibility of the assessors to determine the extent and type of the need and to take that need into account (and record it in the 12th care domain) when deciding whether a person has a primary health need*".

As an SCI person, you have care needs associated with a variety of SCI features, some of which do not occur in other medical conditions, and you should achieve scores for each of these, resulting in an overall score for this domain. You should read and direct assessors to '*Emergencies and Potential Complications of Chronic SCI*' – In: '*Managing Spinal Cord Injury: Continuing Care*', Chapter 24 (2006), available from SIA. Under this 12th domain emphasise your other needs in areas such as:

- **Autonomic dysreflexia.** A risk of AD occurs in lesions above T6, both in complete and incomplete SCI. This warrants a '**Severe**' score because it needs to be treated as a **medical emergency**, as it is potentially life-threatening. Average systolic blood pressures (SBP) of 90 -110 mm/Hg in SCI patients can rapidly become severe hypertension (SBP over 300 mm/Hg). It is important to stress (i) the **unpredictability** of AD, with its sudden onset 'out of the blue' and its rapid progression, (ii) the risks associated with AD (fatal cerebral haemorrhage, 'status dysreflexia') if not resolved speedily, (iii) the many and disparate causes of AD, and (iv) the skill, knowledge and training needed by those who provide care to you (their knowledge must encompass not only the condition, how to recognise incipient AD and how to resolve it, but also how you react to AD as an individual) . Status dysreflexia refers to the state of prolonged, heightened susceptibility to AD that can ensue after an initial attack.

Assessors may 'downplay' your need if you haven't experienced AD recently, but you should counter this by pointing out it is because your need is being well-managed. Even if it has been some time since your last episode, you remain at risk. An attack can also occur even where there is no history of previous episodes; in this event, you lack the experience to identify or deal with the symptoms or cause of the attack. It is advised that you carry GTN sub-lingual spray or other prescribed vasodilator such as nifedipine with you at ALL TIMES, so point this out. Remember you need assistance to take this medication if you are tetraplegic because of lack of manual dexterity and (arguably also if paraplegic) as your level of cognition may be impaired to an extent that you cannot self-medicate.

You should ensure that assessors recognise that the risk of AD interacts with, and can lend support for a higher score under, Cognition, Skin & Tissue Viability, Continence, and Drug Therapies & Medication domains. Make sure that assessors understand the wide range of disparate causations of AD and the interactions with other care domains. Supply your assessors with a copy of SIA's Autonomic Dysreflexia Factsheet. Also point out that as a condition peculiar to people with SCI, it is highly probable that those treating you as a result of an emergency admission to hospital following an attack, would not be knowledgeable about it or necessarily know how to recognise it and deal with it

- **Involuntary muscle spasms.** Stress the effect on your life and well-being, including if you injure yourself or others or fall– from your wheelchair. Stress the unpredictability of your spasms.
- **Postural hypotension** often occurs in SCI lesions above T6 when they go from a lying to a seated/vertical position. It results in feeling faint, and unsteady, and can predispose to a fall. It occurs because of low blood pressure resulting in inadequate blood supply to the brain, and is a consequence of your lack of skeletal muscle pumping in paralysed legs and cardiovascular changes as a result of your injury. An excellent discussion of the topic is to be found at: Claydon et al (2006): *Orthostatic hypotension following spinal cord injury: understanding clinical pathophysiology*, Spinal Cord Vol. 44, pp 341-351.
- **Choking.** There is a risk of choking because your respiratory muscles below your lesion level are paralysed, and your ability for coughing (forced expiration) is severely impaired. Consequently, you are at risk of choking, and may need the assistance of a PA/carer to clear your airway. This is called *Assisted Coughing*, a term used to describe the way an individual can replace the function of the paralysed expiratory muscles by creating increased pressure underneath the working diaphragm. For details of technique, see: www.spinalinjurycentre.org.uk/information/pdfs/019.pdf
- **Temperature regulation.** People with high lesion SCI suffer from poikilothermic syndrome which is related to their decreased ability to regulate body temperature. This can be life threatening, necessitating adequate safeguards to assist in maintaining body temperature. Point out that because of the level of your SCI, you are at great risk of adopting ambient environmental temperature so can quickly become hypothermic or pyrexial if not protected from extremes of temperature. An SCI person with poikilothermia may have sweating, vasoconstrictive, and shivering thresholds of 38.3, 34.4, and 31.8 degrees Centigrade, respectively, compared with 'normal' equivalents of 37.0, 36.4 and 35.6 degrees Centigrade, due to their impaired thermoregulation.

Record your typical temperature. It is important to use core temperature (measured in the ear with an appropriate device) and not rectal or mouth to monitor temperature.

Hypothermia is a common cause of incoherence and loss of brain function in people with spinal cord injury. Care-givers should be alert for early symptoms of hypothermia in SCI people (of which they themselves may not be aware) and undertake preventative measures, e.g. ensure drinking warm fluids and preventing heat loss. This inability to regulate/control your body's temperature, or to regulate the temperature of your environment (e.g. inability to turn up a room thermostat, put on a coat) or to assess risks without the assistance of a carer/PA is a need that should be recognised.

A tetraplegic does not sweat normally, and so may not realise at an early stage that s/he is overheating, only becoming aware of the problem when starting to feel dizzy, faint, or developing nausea, palpitations or 'seeing blue',

- **Risk awareness.** Lack of awareness of risks involving hot water, hot objects, pressure damage or mechanical injury to areas of your body over which you lack sensation are relevant factors in maintaining your safety and wellbeing, as is your lack of awareness of becoming hypo- or hypothermic due to your impaired thermoregulation. Few if any of these factors will be obvious to your assessors, so point them out.
- **Syringomyelia.** The post-traumatic development of a cyst (syrinx) within the spinal cord is a not uncommon feature of SCI and can lead to further paralysis, weakness and loss of function; it is usually confirmed by a MRI scan. If you are unfortunate in having a syrinx, its effect on your psychological wellbeing, mobility, level of dependency and activities of daily living should be highlighted, especially if there is evidence of progressive- loss of function or sensation.

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. 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:

*"...If, after considering all the relevant evidence, it proves difficult to decide or agree on the level, the MDT should choose **the higher of the levels** under consideration and record the evidence in relation to both the decision and any significant differences of opinion". (Paragraph 22, National Framework for NHS Continuing Health Care and NHS Funded Nursing Care 2012)*

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 if you experience it, especially if it occurs regularly. 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

"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)" (Paragraph 90, The National Framework for NHS Continuing Healthcare And NHS Funded Nursing Care 2012).

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) have produced a Statement on Tetraplegia in respect of NHS continuing Healthcare. This is available from the SIA Continuing Health Care Advice Service.

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

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/PCT to check for accuracy, citing

'A copy of the completed DST (including the recommendation) should be forwarded to the individual.....together with the final decision made by the CCG, along with the reasons for this decision' (Paragraph 20, Decision Support Tool for NHS Continuing Healthcare)

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).

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 Advice Line 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 **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 Continuing Healthcare Advice Service may 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 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, Iron. 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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