UNLOCKING THE SECRETS OF NHS CONTINUING HEALTHCARE

Gary Evans

PREFACE

Governments of all political persuasions are naturally disinclined to reveal too much to the general public. After all, information is power and those that aren't well informed can face an uphill struggle when it comes to dealing with government agencies.

Such is the case with the NHS and Continuing Healthcare (CHC).

This guide relates to CHC applications and appeals for adults living in England and Wales. In Scotland and Northern Ireland, the NHS no longer provides complete funding under CHC, meaning that applicants will have to pay for social care and accommodation costs.

In England, CHC is the responsibility of Integrated Care Boards whist in Wales this function is provided by Local Health Authority Boards. For ease of reference all these differently named NHS organisations will be referred to as local health authorities (LHAs).

LHAs are responsible for the planning and commissioning of local healthcare services but they're also responsible for promoting awareness of CHC. However, as LHAs are the very same organisations that have to bear the cost of CHC funding, it's easy to see why this isn't being actively promoted in local hospitals, hospices, GP surgeries or care homes. Consequently, few people have ever heard about CHC and the government wants to keep it that way.

I decided to write this guide for a number of reasons. Firstly, as a retired nurse with extensive experience of the CHC process, I've witnessed the methods used to downplay or diminish needs, thereby denying eligibility for people who rightly should have had their care paid for by the NHS. Instead, people were being told they only had social care needs and this means being financially assessed to see how much they can contribute towards their care. For many, it meant using all their savings and selling their property in order to pay for the support they needed.

Secondly, my own struggle to get CHC for my mother. She was diagnosed with vascular dementia and within just a few months needed round the clock support which could only be provided in a care home. I knew from the outset this was going to be difficult. LHAs automatically consider dementia as social care, even though the wide-ranging needs are frequently complex, intense and often unpredictable. The initial assessment claimed my mother did not have what is termed a 'primary healthcare need' and so an appeal was lodged. The LHA overturned the decision but only awarded CHC for half the period in question. This is a tactic often used by LHAs to limit their liability in the hope that an arbitrary cut off point will satisfy the applicant or family but I wasn't fooled and so a further review took place which found my mother eligible for the entire period. It took a lot of hard work, reading through every line of her care records to build a proper picture of the extent of care she needed, backed up by clinical research. In some ways we were lucky as my mother's LHA wasn't one of the particularly mean-spirited ones that people often encounter by dint of nothing more than their postcode. For example, if you live in west Berkshire the LHA has an established reputation as the most parsimonious in the whole of England with an average eligibility ratio of just 10 people per 50,000 of the population. Compare that to Blackpool's ratio of 152 people per 50,000 and you can see that CHC really is a postcode lottery. In 2017 the National Audit Office stated this practice was unjust and should stop. However, five years down the road and nothing's changed. Unfortunately, until CHC is truly independent of LHAs, the lottery will continue.

My third and final reason for writing this guide is to give you practical advice on the CHC process from someone who has been on both sides of the fence; as an advocate for a relative and a retired healthcare professional.

It's written in the context of a person suffering from dementia (of all types) but the principles can be applied equally to anybody with a different neurological condition, physical illness, disability or injury.

You can find a great deal of information on CHC through the web but for the most part it only scratches the surface and doesn't pull together all the essential information into a single and comprehensive practical source. The devil's always in the detail and CHC's a complicated process with many traps to watch out for.

Whilst I hope the information in this guide gives you everything you need to present the best possible case for eligibility either at the assessment stage or on appeal, I'd be happy to support you or your loved one through this process if you'd like me to do so. Details are available at my website: www.chc-consultancy.com

I wish you well with it.

Gary Evans

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CHAPTER 1

WHAT IS NHS CONTINUING HEALTHCARE (CHC)?

In essence, CHC is a package of care funded by the NHS outside a hospital setting for adults who have significant physical or mental healthcare needs arising from a disability, injury or illness. These needs can be chronic (long term) or acute (short term). Eligibility does not depend on a diagnosis but rather the needs arising from that, nor does a person have to be in the last few weeks or months of life in order to qualify. In theory anybody with significant physical or mental healthcare needs should qualify and the NHS will fund the cost of their care no matter whether the person is still living in their own home or has moved into a care facility. Nor does care have to be given by a registered nurse. CHC is not means tested although some state benefits such as attendance allowance will have to stop on receipt of CHC funding. Once eligible, CHC will be reviewed promptly after three months and then again at twelve months. The purpose of this is to see if needs have declined and if so then eligibility could be withdrawn.

CHAPTER 2

THE HISTORY OF CHC

CHC has never been a legally defined state benefit in its own right. It's simply an extension of full NHS care into a community setting and has been around since the formation of the NHS in 1948. Prior to 2007, local health authorities applied their own set of criteria for somebody needing CHC and this resulted in a myriad of judicial reviews and ombudsman complaints. By far and away the most important case was that of Pamela Coughlan back in 1999 and the ruling of the Court of Appeal remains just as valid today as it did then. This paved the way for the creation of a national standardised approach to eligibility, although it took another major court case and more ombudsman decisions before the government finally had to act. So, in 2007 the government published The National Framework for NHS Continuing Healthcare and NHS Funded Nursing Care. In Wales there is a slightly different Framework but the essential criteria and features remain the same. There have been four amendments to the English version, in 2009, 2012, 2018 and 2022 containing minor changes to reflect improved guidance and new legislation but in some respects the changes have not provided much clarity to an already opaque and complex process. It is important to note the Framework has no legal standing by itself. It makes reference to a number of statutes and case law to assist health and social care practitioners apply the guidance equitably, but as you'll see later on this is not always the case. In July 2017 the National Audit Office report into CHC found wide variation in how the Framework was being applied and claimed the process was yet another example of an NHS postcode lottery. Despite assurances from the Department of Health this issue would be resolved, to date nothing has changed.

CHAPTER 3

HOW DOES IT WORK?

The Framework and legislation make it clear that if a person appears to have needs arising from a health condition, they must be assessed for CHC. However very few people are offered an assessment and this is another failure of the NHS and social services to promote and educate their workforce about CHC as required by the Framework.

The golden rule is - if you don’t ask for an assessment, chances are you won’t be offered it. All assessments must include the individual but when mental capacity or other reasons prevent this, then relatives or carers should be involved. The assessment will seek to determine if the individual concerned has a ‘primary healthcare need.’ There’s no legal definition of this phrase but in essence it means that if the main reason for care is to address significant needs arising from a health related condition, then it can be safely argued that a primary healthcare need has been established and thus the individual concerned is eligible for CHC.

If your loved one has died but you believe they should have been assessed for CHC, you can make a retrospective application and, in these cases, you’ll need to contact your local LHA to begin the process. Applications cannot go back beyond April 2012. The LHA will gather all the care records and produce a Needs Portrayal Document (NPD) which you’ll be asked to check for accuracy. Once you agree it, the LHA will then assess the various levels of need from the NPD but unlike the normal CHC process, relatives are not invited to join that assessment, known as the ‘Multi-Disciplinary Team’ meeting (MDT). However, you still have the right to appeal if eligibility is denied.

CHAPTER 4

THE PROCESS

‘Fast Track’

I’m going to talk briefly about something called Fast Track because it’s a process that rarely causes disputes but nonetheless if you’re not aware of it, chances are you may not benefit from it.

This assessment can only be used when a person is nearing the end of their life and has healthcare needs caused by a rapidly progressing illness or disease with a prognosis of less than three months. It removes the need to go through the multi-stage assessment process and must be accepted by the LHA as evidence the person has a primary healthcare need and cannot be refused or delayed.

The form can only be completed by a doctor or nurse who is directly providing treatment or care for the individual.

The LHA cannot challenge the clinical judgement of the doctor or nurse but can return the form if further information's required in order to clarify matters.

Fast track applications have to be approved by the LHA within 48 hours and must accept the wishes of the individual or relatives in terms of where that person wants to receive their end-of-life care. If that's in a hospital or hospice then obviously you won't be charged for the care you need. Hospitals prefer to transfer end of life patients to hospices or care homes, particularly if death is not imminent.

But if the individual wants to die in their own home as many prefer to do, or in a care home, the Framework provides for this and LHAs cannot refuse to fund care in either of these settings although they may attempt to place the person in a care home that is more cost effective. If this means family having to travel a long way then it's entirely reasonable to go back to the LHA and state that you have the right to enjoy a family life and ask them to find an alternative closer to home.

If the person wishes to die in their own home, you should be cautious if the LHA states that CHC funding will cover a few visits per day from carers and a district nurse. From experience this is wholly unsatisfactory because if medication no longer works or new symptoms develop, nobody should be expected to suffer while waiting many hours for the district nurse to arrive. Equally if the person is incontinent, they shouldn't have to lay in their own urine or faeces until the next carer or carers arrive, nor should the burden of this be placed on relatives. The package of care the LHA are willing to fund must take into account all of these issues. There are a number of private organisations that can provide live-in nursing and live-in carers. This is a particularly attractive option where there are complex and unstable healthcare needs that require the prompt intervention of a registered nurse or trained carer to avoid unnecessary suffering and maintain personal dignity.

The Checklist

For those who don't need fast tracking there's a two-stage process beginning with a document called the 'Checklist.' Depending on where you are, this can be completed by a registered health or social care practitioner trained in its use.

If you're in hospital then ask the ward manager (Sister or Charge Nurse) to organise this. You may have significant ongoing healthcare needs that should automatically lead to an assessment before you're discharged. However, few if any take place and the reason for this is down to a letter the NHS sent to all LHAs in 2017 telling them they had to reduce the number of hospital based assessments for CHC to 15% or less. The rationale for this is easy to understand - it's simply trying to avoid delayed discharges and free up bed space. All NHS hospitals employ discharge nurses and bed managers and they're focused on one thing – getting people out of hospital as soon as possible. Therefore, if there's the slightest hint that you have on-going healthcare needs after discharge, you're quite within your rights to refuse to leave until a checklist has been completed or agreed to in the community.

If you may have qualifying needs and require an assessment, the Framework makes it very clear that after discharge the NHS is still responsible for funding all your care until the outcome is known, no matter where you receive that care. It is for the hospital to ensure that your needs can be met on discharge and the care provider is made aware they will be charging your local LHA, not you.

In other words, you are not personally responsible for funding your care outside of the hospital until such time as the checklist or full assessment has taken place. In order to help achieve a reduction in hospital based checklists and delayed discharges, the NHS has begun to introduce what are known as ‘Pathway’ or ‘Discharge to Assess’ beds. These are beds in nursing homes for patients who have on-going healthcare needs and require a checklist or full assessment. This will usually take place a week or so after discharge to allow the person to settle in but during that time the NHS will pay the care provider.

If the checklist is passed the NHS will continue to pay the bills until the next stage of the assessment, usually a week or so thereafter.

You shouldn’t be asked to enter into any contract with the care provider until eligibility for CHC is determined one way or the other. There have been instances where social services will try to conduct a financial assessment before a Checklist is completed. If this happens, remind them that in all instances where there’s an indication of ongoing healthcare needs, a person must be fully assessed for CHC before being asked about their financial ability to pay for care. If you’re not in an NHS hospital but appear to have healthcare needs then you can ask your GP, LHA, care home or social care practitioner to complete a checklist for you.

The document lays out 11 healthcare domains that need to be assessed, i.e., breathing, mobility, continence etc. Within each domain there are three groups of descriptive phrases labelled A, B and C. The assessor has to indicate which description best matches the needs of the person. For example, when assessing a person’s breathing, if there’s no concerns then option ‘C’ would be selected. However, if the person has a tracheostomy (a breathing tube in the neck) or they are breathless and it limits their daily activities then ‘A’ would probably be selected because it demonstrates a significant healthcare need. Option B would indicate some needs between A and C. The checklist doesn’t require a great deal of evidence to support this. It’s only used to indicate whether a person has needs that suggest they may be eligible for CHC. If the person achieves any of the following scores then the checklist has been ‘passed’ and triggers the next stage of the process, known as the multi-disciplinary team (MDT) assessment:

- One A (only if marked with an asterisk)
- Two or more A’s or
- One A and four or more B’s or
- Five or more B’s

The LHA must organize an MDT and make a decision no later than 28 days after receipt of the Checklist.

The Multi-disciplinary Team meeting (MDT)

The MDT meeting is the acid test for eligibility and it's something you need to be thoroughly prepared for. I can't stress this point enough. Naturally, the individual being assessed will be invited to join the meeting but family members should also attend particularly if their loved one lacks capacity or isn't able to advocate for themselves. You're entitled to bring anybody to the meeting including an independent healthcare professional, solicitor or family friend provided consent has been given by the individual being assessed or where consent has been granted via an LPA or deputyship for those lacking capacity. Although you don't have to, it's simple politeness to let the LHA know who's joining the meeting beforehand. Don't be put off if the LHA or the CHC nurse assessor appointed by the LHA objects. They cannot refuse, nor should they ever say that third parties are not allowed to contribute to the discussion. If they do, ask them where this is stated in the National Framework.

The first thing you must check before agreeing to a date for the MDT is who exactly is going to attend from the LHA and social services. The Framework outlines a couple of options. The MDT can be made up from two healthcare professionals from different healthcare backgrounds i.e., a nurse and a physiotherapist or nurse and a doctor but it can never be two people from the same profession, i.e., two nurses. Alternatively, the MDT can be made up from a healthcare professional and a person who is responsible for assessing people under the Care Act 2014, which is usually a qualified social worker from the local authority but it does not have to be. Due to vague and contradictory wording in the Framework, this could be anybody who has had some training in social care assessments even if they are not professionally qualified and increasingly, LHA's are employing people in these roles rather than reaching out to local authorities asking for a social worker to make up the MDT. In doing so this runs the very real risk of allowing the LHA to 'load the dice' in their favour by making decisions on social care by the health authority which is not their remit.

Before agreeing to an MDT, it's advisable to ask about the experience and knowledge of the CHC nurse assessor. Does that person have sufficiently good understanding of the health conditions of the applicant? To give proper and fair consideration to the needs arising from a specific diagnosis (not the diagnosis itself) the nurse should ideally be a specialist in it, or at the very least have worked in that particular field of nursing for a number of years and be up to date with their knowledge. Otherwise, you're asking somebody to make judgements with little or no understanding of the issue and that could adversely affect the outcome of the assessment.

It's the same analogy as asking a chiropodist for their professional opinion on kidney disorders. Not a good start.

A report by the Continuing Healthcare Alliance found that 60% of healthcare professionals are assessing people for CHC without sufficient knowledge of the medical condition they are looking at. Unfortunately, you can't insist on the chair having specialist experience or knowledge but at least it demonstrates to the nurse and the LHA you're aware of the potential limitations in their ability to properly assess individual needs and useful ammunition if you need to appeal.

I recommend you record the meeting. From personal experience I can recall instances where key evidence was discussed but never appeared in the final report or comments noted that didn't reflect what was actually said or promises made that were later broken. You don't need consent nor should you disclose your intention to record as it's likely the LHA will refuse to proceed until you agree not to record the meeting. LHA's are extremely nervous about this and for good reason because it gives you leverage to hold them to their word.

When ex-president Bill Clinton ran for office, he was famously quoted as saying "It's all about the economy, stupid." This catchphrase couldn't be more relevant to the MDT because in this instance, it's all about the **evidence.** Without it you're facing a monumental uphill struggle. But what is evidence in the context of CHC? Simply put it's the record of care.

I've seen many potentially good cases fall at the first hurdle due to poor documentation. Detailed and comprehensive records are absolutely **essential** tools in demonstrating the level of care the individual needs. For example, if the record shows that *'Mrs X was helped out of bed'* when in reality she has to be hoisted with two carers because she cannot stand, then it's pretty much an own goal. The same can apply at meal times. If it was noted that Mrs X *'had lunch'* when in reality she needed feeding and it look a long time, then you can see how poor records can easily undermine the strength of a case.

You'll often find carers don't have the time or inclination to write detailed notes and this is unacceptable practice which should be challenged with management immediately.

You should ask to see the records before the meeting to acquaint yourself with the type and amount of care you or your loved one needs. Look for and note down episodes of care that demonstrate intensity, complexity or unpredictability. That way, if the MDT attempts to gloss over, skip, downplay or marginalise a specific need, you can point to the evidence and remind them it needs to be taken into account. If you don't find the evidence and ensure it's recorded, you're putting the whole assessment at risk.

If the individual has poor mobility and often falls, is there a record of the falls history and has a risk assessment been completed? If they're at risk of malnutrition, do they have a food chart? How often are they weighed? Is a dietician involved in the care?

What's their 'MUST' score? (Malnutrition Universal Screening Tool) and has it been correctly calculated? What's their 'Waterlow' or 'Braden' score (used to calculate risk of pressure ulcers) and has that also been correctly calculated?

If they have behavioural problems are these being recorded on a behaviour chart? How often does this occur and what interventions are required to manage it?

Conversely if you're the main carer, keep your own comprehensive records. If there are incidents of challenging behaviour, note the date, frequency and extent of the intervention needed to address the problem.

Simply writing; *'Mum was upset this afternoon'* doesn't evidence anything. It's better to write down; *'Mum had an episode of anxiety this afternoon lasting more than three hours requiring constant re-assurance and wasn't able to be left alone due to the risk of her trying to mobilise independently when she is at high risk of a fall.'*

And finally, many CHC nurse assessors will try to impose an arbitrary time limit for the MDT. I know of instances where the family were told they can have an hour but no more. There can never be a time limit placed on this process. The most important person in the room is the applicant or their family representative if they can't attend, not the MDT members and you should point out the meeting will take as long as necessary to ensure all domains have been properly and thoroughly discussed.

I appreciate this sort of approach is rather combative but MDT meetings can be emotionally charged and frustrating, particularly if there's a difference of opinion between you and the MDT. However, by demonstrating you've done your research it reminds them you're not going to be a pushover. You'll need to keep a cool head and remember that whilst you have every right to attend and give your opinions, which must be taken into account, you can't insist they agree to everything you want.

The Decision Support Tool (DST)

Instead of referring to the Checklist again, the MDT will use a more detailed document called the Decision Support Tool (DST). It's an unfortunately worded phrase because by itself it cannot be used to make a decision on eligibility. Too many CHC assessors use the DST mechanistically instead of applying their professional judgement and experience.

Instead of 11 health domains listed in the Checklist the DST has 12, the last one being to account for any other condition not previously addressed. Whereas the Checklist only had three different descriptions of need for each health domain, the DST has up to six, from 'no need' to a 'priority' need. In between you have four other scores: low, moderate, high and severe. In order to establish clear eligibility, the DST must record at least **one** priority level or **two** severe levels of need in any of the 12 domains.

The DST has come in for justifiable criticism as it does not accord the same range of scores for every health domain.

For example, the best score you can get in the communication or psychological and emotional needs domain is high, yet under the drug therapy domain you can score a priority level of need. For many people with dementia this is an artificial barrier.

The highest score you can get for cognitive needs associated with this condition is severe yet this progressive disease can certainly justify a priority score, particularly if the condition has resulted in complete loss of short **and** long term memory, a point the descriptions don't address.

Another example is the nutrition domain which states that for somebody to have a severe need (there is no priority need) they must be unable to take food and drink by mouth and all nutrition has to be given by artificial means requiring skilled professional intervention or monitoring over a 24-hour period, for example by intra-venous fluids or naso-gastric tube. If this description is used as a benchmark by the MDT, the person would have to be at the point of death in order to qualify. This is not the threshold at which CHC is intended to be made available.

MDT members need to agree on a particular score but where there's disagreement then the Framework makes it clear the next higher score must be selected and the disagreement noted. By way of a practical example, let's assume the chair felt the individual had a 'moderate' level of need in his/her behaviour domain but the other healthcare professional or social care practitioner (if attending) disagreed and felt the correct score should be 'high' because the individual's behaviour did not follow a pattern and there was risk of harm to self or others. This should then result in the latter score being recorded with a note explaining why there was a difference of opinion **and** what evidence was used. The latter point is essential because it is common practice for the chair (who ultimately writes up the report) to overrule other MDT members and 'conveniently' forget referencing the evidence which lead to the disagreement. If you need to appeal, this omission is fatal to your chance of overturning lower DST scores because the LHA will claim there was no evidence recorded in the MDT report. If you witness disagreement between MDT members make sure the chair knows they must reference the evidence and then apply the higher score in the report. Another good reason to record the meeting.

At the end of the session the MDT will briefly discuss the matter in private before coming back into the room to give you their decision. If it's 'no' you won't be given an opportunity to challenge it there and then. The chair will tell you to wait for the formal decision letter which will include a copy of the DST that he or she will need to write up.

CHAPTER 5

THE FOUR KEY QUESTIONS

According to the Framework, a person can still be eligible for CHC if they score one severe level of need with other high or moderate scores. Even a large number of high or moderate needs can also be sufficient to indicate eligibility.

The overwhelmingly majority of applicants fall into these categories and when this occurs, the MDT has to consider the following questions for each assessed domain:

- What's the nature of the person's need?
- Are there any elements of intensity?
- Are the person's needs complex?
- Is there evidence of unpredictable needs?

If there's evidence of intensity, complexity or unpredictability in any of the domains then eligibility should be established. It's not necessary to demonstrate evidence for all the questions, one is enough. However, the odd one out is the question relating to the 'nature of need.' Unlike the others it's not a yes or no answer because it's asking about the person's overall condition and the quality of care required to meet the identified needs.

The MDT will not address these questions during the 'open' part of the meeting. Once the domains have been assessed the MDT will retire in private to discuss these. Unfortunately, you don't have a right to contribute to this discussion, leaving it open for the MDT to downplay and marginalise the identified needs, thus allowing them to deny eligibility on these grounds as well as DST scores.

The only route available for you to challenge the outcome of the four key questions is through an appeal, once a formal decision has been made in writing. Often MDT's will acknowledge there is *some* evidence of complexity, intensity or unpredictability they may well attempt to downplay and marginalise these by claiming they aren't significant enough to justify eligibility. Unfortunately, neither the DST nor Framework provide a definition of what constitutes a significant need and leaves it to the discretion of the MDT. For example, when addressing the question of intensity, the MDT might suggest that as care is not being given throughout the day **and** night, it cannot be a significant need and I've seen this tactic used many times before. However, if the care records show that person has to be checked every few hours due to risk of falls or incontinence then you have a strong case to contest that assumption. The DST reminds the MDT that it should consider the totality of needs when addressing these key questions. In practical terms this means that even if there are low levels of complexity, intensity or unpredictability, or interplays between them, when taken in **totality** it may well indicate eligibility and is a very powerful argument to deploy on appeal.

All care homes must ensure they have undertaken their own detailed assessment of a person's needs but sadly I have seen many examples of half completed illegible handwritten assessments which do absolutely nothing to evidence the level of care or properly record it.

It's vitally important that you review all the assessments and raise any issues with management immediately and definitely before the MDT meets to conduct the DST. Again, it's all about how good the care records are.

I would also recommend that you do some research into the health condition and find evidence by way of authoritative clinical sources that support the existence of intensity, complexity or unpredictability and insist this is noted for the record.

You can find a wealth of information on the web and through this site; https://www.nice.org.uk/guidance which provides useful material and links to academic evidence. It's hard work but it shows you've prepared your case thoroughly and won't be a push-over.

If you don't discuss these questions, the CHC assessor (the chair) will address them when writing up the full recommendation at a later stage when neither you nor other MDT members are present. If they're minded to justify ineligibility, this gives them ample time to consider how to word the responses in such a way as to downplay and minimise needs. Having this discussion and evidencing elements of intensity, complexity or unpredictability in the 12 assessed domains makes it difficult for the chair to subsequently claim otherwise.

The stark and brutal reality is that most if not all borderline cases are turned down at the MDT stage and in the next chapter, you'll see how the four key questions can be downplayed and minimised to illustrate the person only has social care needs and thus not the responsibility of the NHS. The deft manipulation of language, cherry picking and even ignoring evidence to portray needs as purely social in nature is thoroughly endemic and by far and away the biggest hurdle for applicants to overcome.

LHAs are under immense finance pressure so it's reasonable to conclude that when an applicant for CHC presents with borderline healthcare needs, the default position is to deny eligibility and let the person or their representative battle it out through the appeal process which is complex and extremely time consuming.

Appeals can take months if not years to complete and this gives LHAs breathing space in the hope that many will give up or have died whilst waiting. Simply put, LHAs hedge their bets. It should be pointed out that in the latter case you can still pursue an appeal and you can also ask the LHA to undertake a retrospective assessment if you think your loved one should have qualified. Bear in mind the financial impact that just one individual with a long-term healthcare need can have on an LHAs budget. A year's worth of care in a nursing home is likely to cost between £50,000 to £75,000 or more depending on where you live. That's a lot of money for the health authority to spend on just one person.

To evidence this I've copied an extract from Dorset GGC's Continuing Healthcare Annual Report 2017-18 in which they say;

'Table 1 shows how, through effective contract management and robust commissioning practices, the CHC team have been able to maintain average costs at the same level as 2016, following a month on month increase in the preceding year.'

For 'effective contract management' read 'keeping care home charges down by finding the cheapest provider' and for 'robust commissioning practices' read 'deny all borderline CHC cases to save on our CHC budget.' Does it sound rather cynical? Perhaps so, however I like to think that a cynic is what an idealist calls a realist.

But moving on, in the next section we're going to show how each of these questions are dealt with and by way of example, we'll talk about a person suffering from dementia and the needs arising from it.

Each question has two possible outcomes, the first is a fair and accurate interpretation of a person's needs and the other, which downplays and marginalises them. How these questions are addressed is a critical part of determining eligibility.

Nature (aka the quality)

Essentially, this discusses the patient's diagnosis and the quality of care required to manage the needs arising from it.

The MDT might reasonably and fairly conclude that:

'Mrs X has a severe level of cognitive impairment which significantly impacts her overall health and wellbeing across most of the DST domains. She requires regular and timely intervention from ***skilled*** *carers to anticipate* ***all*** *her needs as well as providing social and psychological support particularly during episodes of anxiety that can lead to challenging behaviour. Her condition is progressive. There are recorded episodes where it was not possible to provide the required care. Without* ***considerable*** *skilled support her physical and mental wellbeing is at risk.'*

Such an example clearly indicates the nature of the person's needs demonstrate they are primarily health related and therefore she would be eligible for CHC.

Of course, if the MDT decides to downplay and marginalise the nature of this person's needs, they would come to this conclusion:

'Mrs X has cognitive impairment and needs some help to meet her activities of daily living such as social interaction, washing and dressing. The help she requires is ***routine*** *in nature and typical for a person who requires assistance with care to maintain their safety. Her needs are* ***well managed, stable*** *and for most of the time,* ***not problematic*** *for carers.'*

Often the MDT will say that care is 'routine in nature.' This may be true but it has nothing to do with eligibility for CHC. Instead, this phrase merely describes the ability of the care provider to do their job.

It can be argued that a ventilated patient placed in a medically induced coma receives routine planned care but this does not help address the level of need that patient requires which will clearly demand a great deal of skilled care.

MDT's will also say that care is 'not problematic' to provide. If it is a problem then clearly there's a need that's not being met or the DST score is too low. But if not, then again it merely suggests the care provider is able to do their job and the phrase is irrelevant in the context of the assessed needs of the individual. It's not about the care provider's ability to do their job, it's about the person's needs.

Another tactic is to state that needs are being ‘well managed’ despite the National Framework making it clear that a well-managed need is still a need and cannot be marginalised. In practical terms this means the MDT must consider what would happen to the individual if the intervention **wasn’t** available.

A good example of this is where a person exhibits aggressive behaviour or anxiety that puts them or others at risk of harm. If these issues are resolved with medication or it needs a lot of skilled one to one intervention, they’re being well managed but the MDT needs to look at the problem as if **no** treatment or care was in place.

Only when the problem has been cured or permanently reduced can the MDT conclude there is no longer a need. However, this is open to significant personal interpretation, giving the MDT another opportunity to suggest that in their view, there’s nothing to address.

Stability is also used as an excuse to downplay or minimise needs. However, this is yet another irrelevant word in the context of assessed needs. A person can be described as stable but actually have significant needs. It’s likely they are stable precisely because of care interventions, but without this input they would become unstable thus demonstrating a well-managed need that results in a stable condition.

The widespread use of irrelevant words and phrases used to downplay or minimise needs is common practice in all borderline cases and CHC assessors are trained in how to use stock phrases and terminology to paint a picture that best suits their employers need to keep a lid on costs by ascribing needs as social in nature. This may sound somewhat jaded but from experience I have witnessed these tactics on many occasions.

Intensity (aka the quantity)

This question asks about the extent and severity of the needs and the support required to address these, including the amount of sustained or ongoing care. The correct application of this question would result in the following MDT observation:

*‘Mrs X requires **significant** and **sustained** help throughout the **day and at night** to address her needs across most of the identified domains. She will experience **daily** episodes of **severe** anxiety and distress and during these periods requires **prolonged** re-assurances from carers sitting with her on a **one-to-one** basis.’*

*‘Due to cognitive impairment, she is unable to reliably communicate in **any** meaningful way and carers must carefully interpret verbal and non-verbal signs and must anticipate **all** her needs **all** the time.’*

However, if the MDT wanted to paint a different picture of the intensity of care needed, they could say this:

‘Mrs X requires some help with her daily activities and at night there is a pressure mat next to her bed which will alert staff when she wants help to go to the toilet. She can be anxious

at times but carers are on hand. As her communication isn't reliable carers need to be aware of what Mrs X is actually saying and they are usually able to meet her needs without difficulty. There is no evidence to show Mrs X needs many carers to address her needs or that she requires one person to be with her ***all*** *the time. She has no need for* ***specialist*** *input.'*

Here we can see the MDT clearly marginalising and downplaying needs by avoiding any reference to the amount (or intensity) of care this person needs or addressing the severity.

This question looks at the **totality** of care required each day to meet the person's needs. If the evidence demonstrates on-going care throughout the day and night with frequent interventions across many of the assessed domains, then sufficient intensity can justifiably be claimed. Nor do individual care interventions need to be lengthy. A lot of short term interventions can amount to a great totality of care.

The MDT goes on to say she doesn't need specialist care. The latter point is a common tactic used to paint a totally misleading impression that eligibility requires the input of healthcare specialists. The National Framework expressly rules out the need for the involvement of healthcare professionals as a key component of eligibility criteria and if necessary, you should remind the MDT of this. It is all about the amount of care a person needs and not who is giving it that matters, yet CHC assessors routinely squeeze this in.

Complexity

This question asks how the needs present themselves and how they interact to increase the skill required to monitor the symptoms, treat the condition and or manage the care.

A balanced and fair approach would be to say:

'Mrs X's ***severely*** *impaired cognition impacts upon* ***most*** *of the other care domains and there is satisfactory evidence of noticeable* ***interplay*** *within many of them. For example, she is at high* ***risk*** *of falls,* ***frequently*** *incontinent, unable to reliably express this and will attempt to mobilise independently. Consequently, there is a* ***high*** *risk of skin breakdown requiring* ***regular*** *hygiene and pressure area care and high risk of falling. Challenging behaviour will* ***often*** *result in refusing to eat or take essential medication, thus placing her health at risk and interventions are not always successful in managing this. She has medication that requires* ***skilled*** *care to manage potentially* ***serious*** *side effects and requires monitoring.'*

Of course, the MDT could take an entirely different approach by describing this as follows:

'Mrs X impaired cognition does impact on some of the care domains but these are all being well managed by staff.'There is no requirement for ***more clinically trained*** *staff to become involved and the home is able to provide on-going routine care. Staff did not require* ***extra*** *training, knowledge or skills in order to care for Mrs X, over and above their field of practice. Her medication was neither complex nor did it frequently change.'*

As we have seen in the other questions, the MDT will often avoid the use of adjectives in order to downplay the extent of the person's needs. The Framework reminds us, as it should the MDT, that reliance on clinical expertise is not essential to establish eligibility. The MDT continues to refer to the phrase 'routine care' which as described earlier, has absolutely no relevance. Also note the reference to needs being well managed which again is expressly prohibited in the Framework.

If care staff did not require extra training, knowledge or skills then again this simply means the provider is able to meet the needs of the individual, whether living at home or in a care facility. It's one of many stock-in-trade phrases frequently rolled out to paint an entirely misleading and irrelevant image.

In terms of medication the MDT didn't believe it was particularly complex. Again, this is another area where they can try to pull the wool over your eyes. I'd recommend discussing medication with your GP beforehand or if you feel up to the challenge, you can do your own research online by referring to the British National Formulary, known simply as the 'BNF' which you can access from this link https://bnf.nice.org.uk/ Does the medication require enhanced skills or knowledge to administer? Are there potentially serious side effects? Does it need regular monitoring? Does it have to be given by covert means? If so, this adds complexity to the care required. It will also demonstrate to the MDT you've done your research.

Unpredictability

Last but not least we come to the question about unpredictability and this is concerned with understanding the degree to which needs fluctuate and thereby create challenges in managing them. It also relates to the level of risk to a person's health or others if adequate and timely care is not provided.

An MDT might suggest the following:

*'Mrs X dementia presents carers with **fluctuating** changes in behaviour that is difficult to reliably predict. Although it is noted that some challenging behaviour occurs in the late afternoon, consistent with 'sun-downing' associated with the condition, this is not always the case and there is evidence she can be **frequently** non-compliant with care interventions. Her cognitive impairment and inability to recognise risk means she will attempt to mobilise without support and has fallen on many occasions.'*

*'She therefore requires **constant** supervision during the day and a pressure activated mat by her bed at night to alert staff she is attempting to mobilise. Without such measures and **timely** care, she is at risk of serious injury.'*

If the MDT wanted to downplay and marginalise this question, they could address it by saying:

'Mrs X needs are entirely ***predictable*** *allowing the carers to anticipate and provide interventions supported by routine monitoring. Although she could present with challenging behaviour at times, the pattern of this was known by her carers. Due to her risk of falls, this is* ***minimised*** *by the use of a pressure activated mat and other equipment.'*

Here we can see the MDT completely twisting the meaning of the question. This statement is really trying to say that Mrs X's needs are predictably unpredictable and therefore don't count. Pure sophistry but sadly I have witnessed this being used.

Nobody can predict the unpredictable with any degree of certainly unless they have a crystal ball. In the example above, it is impossible to predict when Mrs X needs the toilet and will attempt to mobilise without assistance, putting her safety at risk. However, this need can be addressed by having carers in constant supervision during the day and with a pressure activated mat at night. Such interventions demonstrate the need is well managed but as the Framework clearly points out, a well-managed need cannot be marginalised. It also demonstrates there's a level of intensity to the care required.

Note the reference to 'timely and adequate care' in the description of this question. If the assessor is minded to downplay and marginalise a need, they'll often avoid addressing this point because it's key to demonstrating the existence of a healthcare need. Not all care needs to be given promptly and by competent staff, but if there's a clear risk to a person's physical or mental health if care isn't given quickly and by people trained to do so, then it must be acknowledged by the MDT.

The DST and Framework remind the MDT that they must take into consideration the likelihood of deterioration and whether it would be appropriate to recommend early eligibility rather than wait for further deterioration and an increase in needs before re-assessing the person. In slowly progressive illnesses such as dementia and other neurological conditions, if the MDT does not recommend eligibility, it should set a date for an early review. However few if any are re-assessed without prompting, so it would be wise to mark your calendar and review the care needs every couple of months to see if there's been an increase or change and if this is the case then ask your LHA to complete a new DST.

At the end of the meeting the MDT will usually retire to another room for a private discussion. On their return, you'll be given the decision and a brief re-cap of the four key questions that hopefully were discussed during the meeting. You'll receive the formal decision in writing a few weeks later including a copy of the completed DST.

If eligibility isn't established on DST scores alone, it's highly probable the reasons for this lay within the answers to the key questions.

Be prepared to see widespread evidence of sophistry, marginalisation, ignorance of Framework guidance and occasionally, I'm sorry to say, outright fabrication. Hence the importance of recording the meeting or having somebody with you who can verify what was said and, more importantly, what wasn't.

CHAPTER 6

THE APPEAL PROCESS

Every LHA will have an appeal's process which may vary slightly but the eligibility decision letter should tell you what your rights are if you wish to appeal.

In general, most LHAs will offer you an opportunity to request an internal review of the decision by way of a two-stage process. The Framework reminds LHAs that internal reviews should be completed in a timely fashion yet don't specify how long this should take.

Consequently, it's not uncommon for LHAs to take months but don't be put off by this tardiness. If they haven't given you a time frame within a couple of weeks of receiving an appeal then remind them they are failing to abide by the Framework. Alternatively, go down the route of making a formal complaint which then allows you to refer the LHA to the Parliamentary and Health Service Ombudsman (PHSO).

Before you lodge an appeal, take your time to review the DST in fine detail, line by line and word by word. You can challenge anything in the DST, from the composition of the MDT, to incorrect scores or how the four key questions were answered. Spending time preparing the basis for your appeal will save having to write again when you suddenly realise you missed something earlier on.

You can also appeal a negative checklist although given the bar is set relatively low it's rare this would ever need to be challenged.

However, it's worth pursing because even in the event of a negative MDT outcome, if you're in a nursing home you will qualify for some NHS assistance called the Funded Nursing Care payment which is addressed later on.

Peer review/local discussion meeting

This is the first stage of the internal review process. A peer review is simply another healthcare professional from the LHA reviewing the DST.

Alternatively, the LHA may invite you to attend an informal meeting to discuss the matter but in practice this is nothing more than an opportunity for the LHA to explain the rationale behind their decision and to address any concerns you have about the process.

You'll receive a decision letter but be prepared for the response to confirm the original recommendation.

Local resolution meeting (LRM)

The next step is called the LRM which you'll also be invited to and it's going to be slightly more formal than the first stage as it's often a recorded meeting. However, some LHAs do not offer this extra opportunity but if they do, it'll be with a couple of their own healthcare professionals whilst others may want a healthcare professional from a neighbouring LHA to attend plus a representative from social services.

The Framework encourages LHAs to resolve the matter at this stage because further appeals are costly for the LHA and the wider NHS. Ideally the LRM provides an opportunity for other health and social care professionals to review the decision.

If you've already done your research for the first stage of the appeal process, then you probably don't need to add anything further at the LRM.

With good evidence there's every chance the LRM will agree to amend any disputed scores. However, in domains where there's a severe or priority score option (cognition, mobility, nutrition, skin, breathing, drug therapies and other significant needs) the LRM will be **very** wary of agreeing to increase the score, particularly if you've already got one severe score as another one, or a priority score, will automatically result in the award of funding.

If you find any evidence that needs have been downplayed or marginalised in the care domains or in the discussion of the four key questions or anything else, now would be the time to raise it. For example, if you produced clinical evidence at the MDT that a particular condition was complex, intense or unpredictable but it was not noted (which does frequently happen) then let the LRM know this could have made the MDT's decision unsound.

The LRM won't give you their decision at the end of the meeting. You'll receive this with a detailed report in a few weeks.

According to the latest data published by the NHS (2022-23 Q2 England), about 17% of appeals are successful at a local level but this is subject to wide variation with West Berkshire yet again the worst offender. Although 17% is a small number, it does represent about a one in five chance of success, so it's worth the effort, more so if you obtain professional representation where your odds of success are likely to be improved.

You may wish to consider obtaining a medical report from a consultant or specialist nurse. This carries a great deal of weight but not all NHS consultants or nurses are willing to do this because it can be seen as a conflict of interest. However, it's worth investigating.

If you can't get help through this route then you could obtain a medical report from an independent healthcare professional.

If you're acting on behalf of the patient, you may have to go through a solicitor who will instruct the independent healthcare professional and you'll need to hold LPA or deputyship for health and welfare.

Independent review panel (IRP)

Where local resolution has failed to overturn a negative outcome, you'll be given the option of asking for the case to be considered by an IRP. There's a six-month time limit from the date of the LRM decision letter to request this review. There's no cost for requesting an IRP.

IRPs are managed by NHS regional offices and occasionally they may refer the matter back to the LHA in order to try and resolve the issue locally.

An IRP will consist of at least three people. The chair is not an employee of the NHS and may be a lay person but he or she will more than likely have senior management experience in private or public sector organisations, excellent analytical skills and experience in chairing meetings. The second panel member will be an NHS representative, usually a nurse from a neighbouring LHA. The final member will be somebody from another local authority social service team. If there are complicated medical matters to consider the panel may ask for clinical advice and that'll be provided by a healthcare professional who cannot give an opinion on the DST scores, nor can they 'vote' when the panel retires to consider its decision. There'll also be an administrator who will assist the panel and take minutes.

Obviously, the LHA will attend to put their side of the case but on this occasion the representatives will be more senior nurses or other healthcare professionals. The irony of course is that these people won't have assessed the applicant personally. They're attending simply to defend the LHAs decision not to uphold the local appeal.

Just like the MDT meeting, if you want to bring a relative, family friend, specialist solicitor or independent healthcare professional, this is fine provided the IRP have been notified in advance. Appeals for an IRP are not automatically accepted. You'll be asked to complete an application form explaining why you believe the appeal has merit and should be heard.

It's important that you explain the kind of care that's needed, how long it took and how often it was required. Be as specific as you can. It helps much more if you say that a problem happened 'usually two or three times a day' rather than saying it happened 'a lot'. Also tell them about anything that made giving care harder or more complicated and if needs were changing or difficult to know in advance. Mental and emotional needs are just as important as physical needs. And remember that care **doesn't** have to be provided by professionals or paid carers. This means that care provided by family members, friends or volunteers carries equal weight.

There are some extremely important points to consider **before** requesting an application form. You have just **six weeks** from receipt of the form to complete and return it. Not only that, but if you want to make a full written representation, which you can and should do, then this must be submitted with the application form otherwise anything you submit later on will be excluded. It used to be the case that IRPs would accept written representations up to the day before the hearing but this is no longer accepted and probably because IRPs were finding themselves inundated with re-written representations.

If you have all the care records and want to dissect the LHAs case line by line, then a written representation is a very good way to go about it and a useful reference tool on the day. Six weeks should be enough time to do this but if you're still waiting for care records or haven't asked for them yet, then my advice is **not** to request an application form until you have everything to hand but do be mindful of the six-month time limit from the date of the LRM.

The questionnaire and any supporting representation will then be considered by the chair who will decide whether or not to proceed with the appeal. All borderline cases should go to panel, i.e., those with DST scores suggesting there might be a case for eligibility and by way of example this means a severe level of need together with a number of high or moderate scores, or a large number of high or moderate scores.

The IRP is relatively informal and the chair will give every party ample opportunity to speak. From experience I would let the LHA do the talking first and then challenge anything you disagree with. Giving a closing statement can also help, particularly if you've done your research and picked apart the LHAs rationale for denying eligibility. At the end of the meeting the chair will ask you and the LHA to leave while they discuss the case. The chair will then write the recommendation which you should receive in about six weeks or so. It's important to note that an IRP recommendation to award CHC is not binding on the LHA but there must be truly exceptional circumstances to justify this.

Parliamentary and Health Service Ombudsman (PHSO)

All's not lost if the IRP doesn't change the LHAs decision not to award CHC or won't offer you a hearing. You'll have an opportunity to refer the matter to the PHSO. This also applies if you disagree with a negative checklist and completed the local appeal process.

If you've been awarded CHC but disagree with the level of funding the LHA are willing to provide, the PSHO can also step in and take a look.

If the PHSO upholds your complaint they will ask the LHA to take action to rectify it but they cannot order them to change their decision, nor does the PHSO make their own assessment on eligibility. However, it's highly unlikely the LHA would dare to rebuff the PHSO without the same exceptional circumstances mentioned earlier, although on this occasion the next stage would be to seek a court ruling which would almost certainly find in your favour and force the LHA to comply.

The PHSO will need to know why the IRP's decision not to recommend eligibility was unreasonable or whether it demonstrated an abuse of process and they will want to know what steps you took to raise your concerns with the IRP about this and what response you received before they will agree to investigate.

Judicial review

If the PHSO doesn't uphold your complaint you may be able to ask for a judicial review in which a judge will look at the PHSO's decision to see if any points of law have not been addressed or incorrectly applied.

The court is not going provide a ruling on the decision of the PHSO. In other words, judicial reviews are a challenge to the way in which a decision has been made by the PHSO, rather than the rights and wrongs of the conclusion it reached. To the best of my knowledge there has been no judicial review of CHC since 1999 in the Pamela Coughlan case which is detailed later on. An attempt to do so in 2021 was denied by a single judge claiming the appellant should have sought a court ruling for his mother's CHC application at the time it occurred, nor did the appellant have standing to bring a claim on behalf of the general population.

Taking the matter to court is without doubt going to be extraordinarily expensive, bearing in the mind the LHA has unlimited funds to fight it. However, it is my view and one shared by many others with legal knowledge of the CHC system that, assuming an individual has a modest range of healthcare related needs not too dissimilar to the Coughlan case, a judicial review would in all likelihood succeed. The real problem is having sufficient funds to get it to court and keep it there should the LHA seek to appeal all the way to the Supreme Court which they would certainly try to do. But a review is long overdue and a successful case would likely have profound implications.

CHAPTER 7

What is the difference between a health and social care need?

For borderline cases, this is the 'million-dollar question' because there's no legally defined difference between the two. What makes it even more difficult is the obvious fact that some health needs will include elements of social care and vice versa. A good understanding of the differences and being able to clearly show that the majority of the care a person requires derives from a health condition is key to a successful application.

Previous editions of the Framework provided some useful guidance but following the introduction of the Care Act in 2014, the Department of Health removed much of that information and replaced it with extensive reference to the Care Act in the 2018 Framework. This deftly moved the goal posts by providing a list of needs that **appear** to suggest social services may be responsible for care in the first instance, not the NHS.

However, the Care Act now requires social services to also consider making referrals for CHC but don't rely on them doing so and in fact it's vitally important to always remember that if you have needs arising from a physical or mental health condition, you should **first** be assessed for CHC, not means tests by social services.

Let's take a look at what defines a primary healthcare need in the context of CHC. The Framework says:

'A primary healthcare need is one relating to the treatment, control or prevention of a disease, illness, injury or disability and the aftercare of that person so affected, irrespective of whether the need is met by a healthcare professional or not. In simple terms, a person has a primary healthcare need, if having taken into account ***all*** *their needs, it can be said that the* ***main*** *aspects or the* ***majority*** *part of the care they require is focused on addressing and/or preventing health needs.'*

The last sentence is fundamental and I've highlighted the three most important words. Essentially this looks at the totality of care you require across all the DST domains and if you have noticeable needs in the majority of them, then arguably you've established eligibility for CHC.

Now let's see what previous versions of the Framework used to say about social care:

'Social care focuses on providing practical assistance in the person's own home or help with equipment and home adaptations; visiting and sitting services, providing meals or facilities for occupational, social, cultural and recreational activities outside the home. It also involves providing assistance with the activities of daily living (washing, dressing, etc), maintaining independence, social interaction enabling a person to play a fuller part in society, helping manage complex relationships and assistance with educational opportunities.'

This helpful definition disappeared in the 2018 update to the Framework but nonetheless it remains a useful benchmark to reference. Particular note should be taken of the points relating to the maintenance of independence and playing a fuller part in society as key indicators of a social care need.

In the context of a person suffering from advanced dementia they will not have the ability to maintain independence or play a fuller part in society, rending an assessment for social care almost entirely meaningless.

CHAPTER 8

Court of Appeal - Pamela Coughlan (1999)

The Court of Appeal found in favour of Pamela Coughlan and her fight to retain NHS funded care following a serious accident which left her with permanent disabilities and ongoing heath care needs.

The LHA decided to close the facility where Pamela was living and told residents the NHS was no longer responsible for their care. This meant that residents would have to be supported by social services and therefore means tested. Pamela contested this decision which led to the Court of Appeal ruling the LHA was wrong to withdraw funding because the criteria used for assessing healthcare needs were too restrictive.

Remember, this was before the introduction of the National Framework when local health authorities were making up rules according to their own agendas thus perpetuating a post code lottery.

The Court held that social services could only provide healthcare that was:

- Merely incidental or ancillary to the provision of accommodation which a local authority is already under duty to provide, **and;**
- Of a nature, which it can be expected that an authority whose primary responsibility is to provide social services can be expected to provide.

Ultimately the Coughlan case highlighted that if an individual has healthcare needs that are over and above that which social services can provide, the NHS has a responsibility to meet those needs and to fund the necessary care. The Framework pays lip service to the Coughlan case because the ruling is still valid, even if some local CHC assessors and LHAs state otherwise.

It's extremely important to look at what the judgement is telling us. It's not about the duty of the NHS to support a person's healthcare because that's enshrined in law and there's no upper limit of care the NHS must or can give. Instead, the Court is saying it's for social services to determine that if the heath needs of the person are beyond that which they can lawfully provide then by **default** the NHS must be responsible. Unfortunately, the Framework suggests the opposite by claiming the NHS is the final arbiter on eligibility for CHC despite optional involvement from social services.

If that were true then it turns case law and ombudsman decisions on their heads. Every CHC assessment **must** be what is termed 'Coughlan compliant' and this is a vital point you should make to the MDT at the start of the meeting. This may irk some of the MDT members, but by reminding them this compliance is part of the Framework, it shows you've done your research and preparation for the assessment.

Let's put aside the Framework and analyse the judgement in plain English.

The first factor the Court spoke about was the reference to incidental or ancillary healthcare. In essence this is telling us that if the healthcare you need is merely incidental or ancillary [to the provision of accommodation] then social services can fund the care or in other words, means test you. But what does 'merely incidental or ancillary' mean? In ordinary parlance this means the issue isn't the main problem, it's just a minor point and the Court was using this to describe a small and insignificant amount of healthcare. So ultimately this tells us that if the amount of **health-related** care you need is of a very low level, when taken as part of the total care you need, then social services can legally be responsible for providing that care.

This is called the 'quantity' test and why it's so important to document the amount of care a person needs, for example being able to demonstrate a person requires frequent repositioning due to risk of pressure sores or frequent reassurance due to anxiety or recurrent challenging behaviour. It can add up to a significant quantity of health-related care and therefore beyond what social services are lawfully able to provide.

The other factor the Court spoke about was the reference to the nature of the care that social services can provide, also known as the 'quality' test.

Effectively this means care provided by a somebody who is not professionally trained and registered, essentially in its most basic interpretation, care provided by a lay person. Only if the healthcare needs are of a low level (in terms of their nature, or **quality**) can social services accept responsibility for that care.

The Court therefore presented two propositions known as the 'quantity and quality' tests. If you recall these terms were mentioned previously when I talked about the four key questions that need to be asked in borderline cases; namely the nature of a person's needs (the quality test) and the intensity of those needs (the **quantity** test). If both of these demonstrate a low level of healthcare need, in terms of quality and quantity then, and only then, can social services be responsible. Complexity and unpredictability were not addressed by the Court and arguably have no legal basis on which to be considered.

You may be saying this is all well and good but what does it mean in practical terms? Well, let's take a look at Pamela Coughlan's needs as they stand if she was assessed today using the DST. The Spinal Injuries Association worked directly with Pamela and produced its own assessment of her needs for each of the 12 DST domains. However, what they didn't do was convert those needs into DST scores. I've taken the opportunity to bridge that gap and complete the DST based on my professional interpretation of her needs as follows:

PAMELA’S DST SCORES

CARE DOMAIN	**P**	**S**	**H**	**M**	**L**	**N**
Breathing				✓		
Nutrition - food and drink	■				✓	
Continence	■	■	✓			
Skin (including tissue viability)	■			✓		
Mobility	■		✓			
Communication	■	■				✓
Psychological & emotional needs	■	■				✓
Cognition	■					✓
Behaviour						✓
Drug therapies and medication					✓	
Altered states of consciousness		■			✓	
Other significant care needs	■	✓				
TOTALS:	**0**	**1**	**2**	**2**	**3**	**4**

As you can readily see, Pamela doesn’t have scores that would automatically lead to CHC funding. She only manages to score 1 x severe, 2 x high and 2 x moderate needs and therefore her overall requirement for healthcare, according to the DST scorecard is relatively modest. Additionally, she does not have any complexity, intensity or unpredictability in her care needs (as defined by the DST) nor does she require the input of healthcare professionals yet it is clear from the Courts ruling that her needs were beyond the remit of social services - but why? The answer is simply that the DST is **not** to be used as a decision maker. It’s just a guide for health and social care professionals. Unfortunately, assessors rely entirely on the DST scoring system and narrative in a rigid, mechanistic way rather than applying common sense and professional judgement. Case law set the bar to eligibility relatively low but the Framework and DST moved the goalposts to create a much higher bar than intended by the Court.

Consequently, whilst the Framework and DST may appear to be Coughlan compliant, it can be used in such a way as to make it non-compliant through strict mechanistic application of the DST narrative and downplaying and marginalising needs in the four key questions that must be addressed when dealing with borderline cases. There is some room to argue the Framework and DST have frustrated the law and added unnecessary complexity and confusion.

Comparing your scores with those of Pamela may demonstrate higher needs but this mustn’t be taken to mean by inference that a person should be entitled to CHC. To do so would be to fall into the same trap by simply looking at numbers and the narrative. Instead, the key is to focus on the two social care tests; the quantity and quality of care a person needs.

Earlier in this guide I mentioned something about the composition of an MDT and why it’s important to have a representative from social services join the meeting to complete the DST. The Framework says the MDT should comprise health and social care staff presently or recently involved in assessing, treating or supporting the individual. The rationale for this is simply to make sure the social care tests in Coughlan can be properly considered.

However, there’s a contradiction in the Framework that has yet to be addressed, namely that an MDT doesn’t need to have input from social services if it comprises two healthcare professionals from different professions. How then can the Framework be Coughlan compliant if the Framework doesn’t mandate the involvement of a social care practitioner that knows, or ought to know, the legal limit of social care by way of the quantity and quality tests?

This is an important reason why a social care practitioner should take part because it’s entirely reasonable to ask that person if he or she knows what the **limit** of social care is. If they don’t then arguably it hands ammunition to the CHC assessor (the MDT chair) to claim a person only has social care needs, thus shifting responsibility to the local authority who will of course immediately means test the individual.

CHAPTER 9

FUNDED NURSING CARE (FNC)

FNC is a payment awarded to those who pass the Checklist but do not qualify for CHC and reside in a care home with registered nurses. It’s tacit recognition that the individual does have some nursing needs which the payment will cover. However, it’s a paradox because eligibility for CHC is not based on the provision of care by registered nurses but FNC is.

The LHA should automatically contact the nursing home and start making payment of FNC which is not on top of the care fees the individual is already paying. Once payments begin the care fees *should* be reduced by the amount of FNC which is currently £209.19 a week in England and £179.97 in Wales.

However, this is entirely dependent on what your contract says about how payment of FNC is treated because not all care providers will reduce the weekly fee by the amount of FNC. Many will claim it’s a top up fee for additional nursing care and simply pocket the extra income. If your contract is silent on how FNC is to be managed then it’s highly likely the care home is in breach of consumer legislation as outlined by the Consumer and Markets Authority guide to care home contracts which is available online.

CHAPTER 10

KEY OMBUDSMAN DECISIONS

The PHSO website provides an online search function for CHC cases but due to long standing IT problems which have yet to be resolved, the results are somewhat haphazard. However, the two most important decisions are as follows:

Malcolm Pointon (2002)

Mr Pointon was diagnosed with Alzheimer's in 1991 at the age of just 51. His wife wanted to care for him at home but the LHA only agreed to fund CHC if he was cared for in a nursing home, citing the argument that he needed care from registered nurses 24 hours a day and his wife and additional carers were not qualified to look after him. The Health Ombudsman (the predecessor to the PHSO) disagreed on both counts. This means that CHC funding cannot be withheld on the basis of where the care is given and has been enshrined in the National Framework ever since.

It also means that care does not have to be given by a registered nurse as the Ombudsman concluded that Mrs Pointon and her helpers were giving care of such high quality as to be equal to if not better than care given by registered nurses.

By deduction this can be taken to mean that for somebody with advanced dementia, the care they need is likely to be of a quality beyond that which social services can lawfully provide.

Pauline Garside (2015)

In January 2013 Pauline Garside was diagnosed with early onset Alzheimer's and sadly passed away just three years later. By October of 2014 it was clear her needs had increased to the point where her husband, Peter Garside, felt she may be eligible for CHC. Unsurprisingly the MDT disagreed and with hindsight Peter realized he hadn't done enough preparation. The LHA tried to stonewall him, distort the facts and generally operated in an obstructive way, no doubt hoping he would give up, but he didn't. In August 2015 an IRP hearing overturned the LHAs decision and awarded CHC backdated to the date of the original MDT decision. Peter then went on to publish his experience and included Pauline's amended DST scores as follows.

PAULINE’S DST SCORES						
CARE DOMAIN	**P**	**S**	**H**	**M**	**L**	**N**
Breathing						✓
Nutrition - food and drink	■			✓		
Continence	■	■		✓		
Skin (including tissue viability)	■			✓		
Mobility	■		✓			
Communication	■	■		✓		
Psychological & emotional needs	■	■	✓			
Cognition	■		✓			
Behaviour				✓		
Drug therapies and medication			✓			
Altered states of consciousness		■				✓
Other significant care needs	■					✓
TOTALS:	**0**	**0**	**4**	**5**	**0**	**3**

Again, as you can see from this DST, just like Pamela Coughlan, there’s no priority or severe scores but she did have a large number of high and medium scores which ought to have meant she was more than likely eligible for CHC. The fact the MDT chose otherwise demonstrates that in borderline cases, the default position is to simply deny eligibility by downplaying and marginalising needs in the four key questions relating to nature, complexity, intensity and unpredictability. This means people are forced into a lengthy and complex appeal process which can drag on for a long time with no guarantee of success.

It would be fair to argue that anybody with borderline scores equal to or greater than Pauline’s should be eligible for CHC and it’s a good idea to reference these cases at the MDT or appeal.

However please bear in mind that identifying scores higher than Pauline’s or even Pamela’s won’t guarantee success in every case but nonetheless they are very powerful tools which would be difficult to dismiss. So, the more preparation you can do for the MDT the better your chance of tipping the scales in your favour.

CHAPTER 11

ADASS /LGA COMMENTARY AND ADVICE

Soon after the introduction of the Framework in 2007, the Association of Directors of Adult Social services (ADASS) and the Local Government Association (LGA) published their Commentary and Advice for social services to use in CHC assessments. It was based on legal opinion in regard to Coughlan and Grogan and how the quality and quantity tests should be applied to determine the **legal limit** of social care.

They stated that where a CHC assessment finds that a person has:

- 2 or more high needs (or needs above high) **and** at the same time,
- 3 or more moderate needs (or needs) above moderate

Then that person should normally be considered to be **beyond** the legal scope of local authority provision and therefore eligible for CHC.

As you can readily see in the DST scores given to Pamela and Pauline, both of them had needs beyond the legal limit of social care according to ADASS.

The guidance states there are situations where overall, the person’s health and nursing needs are incidental and ancillary (per Coughlan) but some of those needs are **not of a nature** that social services can lawfully provide. In these circumstances a jointly funded package of care from the LHA and social services is likely to be appropriate and lawful.

The ultimate decision maker on eligibility remains firmly with the LHA and not social services. However, that’s not to say social services can’t dispute a finding of ineligibility and the Framework makes it clear there should be processes in place in order for inter-agency disputes to be resolved.

The ADASS and LGA guidance identified a significant tension between health and social care authorities. On one hand, the Department of Health produced the Framework and DST which clearly raised the bar to eligibility higher than that intended in case law, whilst on the other hand, the ADDASS and LGA guidance appears to have remained true to it.

This is why it’s extremely important to ensure that a social services representative attends the MDT so you can remind that person there is a legal limit to what they can provide which is usefully illustrated in the DST scores outlined earlier on.

Ask that person if they are aware of the legal limit. For social services to properly discharge its function at the MDT, they must (through case law) ensure that responsibility for care is not unlawfully passed to them and thence to the applicant for means testing. Unfortunately, it’s common practice for the social service representative to take a back seat at the MDT and that may be for a number of reasons. Firstly, that individual may have no real understanding or training in relation to the legal limit of social care and simply rely on the

Care Act 2014. However, that act only outlines a range of needs that social services can lawfully support. It does not identify the **limit** of that support, hence the vital importance of understanding where that line passes from social care to the NHS. The social services representative may attempt to downplay the guidance by suggesting it's out of date. This is a complete red herring because case law has not changed and the guidance was developed in light of independent legal opinion on case law.

It remains just as valid today as it did when first published and you should challenge any attempt to dismiss it by reminding the representative that social services are legally obligated to abide by the guidance and if they don't follow it, you'll make a formal complaint.

In other words what you should do during the MDT or appeal meeting is be prepared to home-in on the inherent tension between the NHS and social services in terms of who has responsibility for the individual. It sounds pretty ruthless but in reality, the LHA will be equally ruthless and do all it can to offload borderline cases onto social services.

The other reason why social services may play a silent part is simply due to the fact the vast majority of applicants have income, savings and property that will be targeted to pay for their care. Under current arrangements, there's no financial burden on social services until a person's savings fall below £23,250 in England and £50,000 in Wales and then, if that person has property this must be used to fund their care either by selling it or asking social services for a Deferred Payment Agreement which will still be available under the new rules. After taking account of any income, social services will fund the shortfall in care fees and place a charge on the person's property which must be sold within 90 days of their death to repay the local authority, although this timeframe is rarely if ever enforced provided the executors make reasonable efforts to sell it.

It begs the question why a person would want to spend their entire working life paying off a mortgage only to see much, if not all of their property value absorbed by care fees. In circumstances where a person has no assets, social services will take over responsibility for funding all the care fees and when this occurs, it's highly likely they'll find the cheapest provider, often miles from family or expect relatives to contribute. In both cases you are **not** required to agree.

If you enter into a Deferred Payment Agreement, social services will also take over responsibility for monitoring your care. They will, in turn, contract with the care provider for this and the funding arrangement. This means they are accountable for any failings in care.

IN CLOSING

My final advice is this. If you have a borderline case, don't give up because it's worth pursuing. The LHA has to show why it believes you or your loved one doesn't qualify for CHC.

Equally as important, social services have a duty to ensure you should not be paying for your care unlawfully, so don’t let them try to brush you off. Make a formal complaint if you think they’ve unlawfully means tested you and refer to case law and the ADASS guidance.

In the end it’s all about quality research, well documented evidence and fine attention to detail, not only at the DST stage but also during the appeal process. Pick apart the LHA’s decision, line by line. Were there any procedural errors? Was evidence ignored? Did the LHA step outside the Framework by amending or introducing new criteria? Keep an organised file of everything and highlight or bookmark important points in documents.

You’ll need to be tenacious and don’t hesitate to ask your MP to help. Use the NHS or social services complaints process if you think an individual involved in the assessment or appeal has not complied with their own professional code of conduct.

It is hard work and may take many months or even years to succeed but if you truly believe you have a case then you owe it to yourself or your loved one to stay the course, as I did for my mother.

Thank you and my best wishes.

Gary Evans