



Beacon Navigational Toolkit

– Guide to Continuing Healthcare Assessments



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Introducing the Navigational Toolkit

This free assessments guide is part of Beacon's Navigational Toolkit which aims to help people going through the long-term care funding process make sense of what can be an overly-complex system. The Toolkit is designed to assist anybody in England who may be requiring long-term care for the first time or are at any other stage of the continuing healthcare journey to understand whether they may be eligible, empower them to make informed decisions and navigate the appeal process where they disagree with a decision regarding eligibility.

These guides have been written by paralegal caseworkers with over a decade of experience in helping people to understand their continuing healthcare assessments, guiding them through the appeal process and providing practical support to health authorities to enable them to improve their procedures. This means that as well as setting out the essential principles of NHS continuing healthcare in an accessible format from various case law, policy and guidance documents, we have also packed these guides full of useful tips gained from over 10 years' worth of experience assessment and appeal support.

Relatively few people in long-term residential care are eligible for NHS continuing healthcare (less than 15%) despite many presenting with a range of social and nursing needs, often requiring 24 hour care. There is no getting away from the fact that NHS continuing healthcare is a complicated area of health policy involving a complex set of criteria based upon legal tests that have been developed as a result of case law. This policy must be interpreted alongside existing health and social care legislation to be fully understood. Assessments are often lengthy and time-consuming, and the appeal process can be daunting and take many months, if not years, to resolve. Furthermore, the poor quality assessments and procedural irregularities that unfortunately arise from time to time can make assessments even more challenging to unravel and appeals all the more complicated.

For this reason it is understandable that many people find it extremely difficult to fully understand their assessment, or to have the confidence to challenge what they believe to be an incorrect decision regarding eligibility. Many people simply do not have the time or energy to invest in reading hundreds of pages of policies and guidance especially when much of their time may be spent caring or trying to arrange long-term care for their loved one. It is therefore not surprising that so many people we have spoken to over the past decade have told us that they simply feel like giving up.

However, we want to give you a clear message from the outset: although challenging and time-consuming, NHS continuing healthcare is not impossible to work through independently. With the right information and guidance, it is possible to gain a sufficient understanding of the criteria and processes to enable you to request an assessment, fully participate in that assessment, understand the Decision Support Tool and have the confidence to challenge an incorrect decision.

It is also important to note that this is not a 'legal process'. The assessment is not a legal document and appeals do not involve law tribunals. At each stage of the assessment and appeal process, the people making decisions regarding your eligibility for NHS continuing healthcare are health and social care professionals, whose job it is to apply a set of health criteria. Therefore it is neither required nor sensible to focus an appeal on the intricacies of case law, when the remit of the panel is to understand the individual's personal health needs in detail and apply health criteria to them.

For over 10 years our aim has been that anybody requiring on-going care as a result of accident, disability or illness has their needs assessed accurately, in detail and at the right time, so that those who have primary health care needs have their care paid for by the NHS. For those people who feel that they are able to proceed without paying for professional support, we would encourage them to do so with the help of our Navigational Toolkit. Due to the complex and specialist nature of continuing healthcare there are unfortunately few advocacy services in the UK specialising in providing practical continuing healthcare support. However, as an ethical social enterprise we are committed to identifying and signposting people to free support services where we know about them and are certain of their quality. For a full list of the free specialist continuing healthcare support services that are available in your area, please visit our website at www.beaconchc.co.uk.

For those people who do not have a free service in their area but feel that they need professional expert support Beacon offers a range of affordable specialist support options. If you are considering paying for specialist advice, advocacy and casework either from us or another firm, we would strongly encourage you to read the section 'Finding Somebody Independent to Guide you Through the Appeal Process' in our *Guide to Continuing Healthcare Appeals*.

The Basics

NHS Continuing Healthcare

NHS Continuing Healthcare is a package of care that some people need to receive as a result of a disability, accident or illness. People who meet the eligibility requirements will have the full cost of their care and accommodation funded by the NHS. Continuing healthcare is available to any UK resident over the age of 18 who is assessed as having a primary health need.

NHS-Funded Nursing Care

NHS-Funded Nursing Care (FNC) is a contribution made by the NHS for residents of nursing homes to pay for the care delivered by a registered nurse.

Following the principles established by the Coughlan judgement (see our guide *The Legal Background to Continuing Healthcare*); Local Authorities were prevented from providing registered nursing services. Instead, the Department of Health introduced Registered Nursing Care Contributions (RNCC) whereby the NHS paid contributions to residents of care homes with nursing. There were 3 RNCC bands; low, medium and high. The band you received depended on the intensity of your nursing needs which were assessed annually.

With the introduction of the National Framework in 2007 RNCC was replaced by a single payment for all residents of nursing homes, known as NHS-Funded Nursing Care (FNC). Residents who had been in receipt of low or medium band RNCC were automatically moved to the FNC single band, currently paid at the flat rate of £109.79. Residents who had previously been in receipt of high band RNCC remained on that rate, currently £151.10.

The key principle of FNC is that the actual care delivered by a registered nurse should be paid for by the NHS rather than by Local Authorities or the nursing home resident. Another important principle is that an FNC assessment should not be carried out until a continuing healthcare assessment has first taken place. FNC should only be considered once it has been established that the resident is not eligible for continuing healthcare.

TOP TIP

If you are currently self-funding your care in a care home with nursing, ask the care home to provide you with a full breakdown in your monthly invoice so that you can check that the FNC contribution is being taken off your bill.

The 'Primary Health Need' Concept

Eligibility for continuing healthcare is based upon the concept of a primary health need, a concept for which there is no *clear* definition and which does not appear in primary legislation. If somebody has a primary health need then the totality of their health and social care needs will be over and above that which could lawfully be provided by social services and therefore the NHS has a responsibility to meet them. Social services are able to provide some health services but not where the overall needs are *primarily* health needs.

This is not an easy concept to apply in the context of an assessment which explains why the application of the criteria is open to individual interpretation, even for professionally trained and experienced assessment teams. Essentially, if the majority of your care is to manage your health

needs or to prevent further health needs from developing, the NHS has a duty to pay for *all* of your care needs and accommodation.

So what constitutes a health need? One might assume that a person suffering from dementia who is immobile and unable to wash, dress or feed themselves independently, who requires continence care and the administration of a medication regime by a trained carer would have a primary health need. This is not necessarily so and such needs are often categorised as social or personal care needs, although we should be careful not to overgeneralise.

The Limits of Social and Community Services to Provide Health Care

If eligibility for continuing healthcare is dependent upon a person having needs *beyond the responsibility of the local authority*, then what are those needs? Without doubt this is a complex area of law and much of the controversy surrounding continuing healthcare has been created by the lack of a simple and authoritative definition. However, it is worth bearing in mind that whilst there is no legal *lower limit* to what the NHS can provide, there is a legal *upper limit* to nursing and healthcare that can be provided by local authorities. Unfortunately this leaves something of a grey area between the two.

What is the legal upper limit of healthcare that can be provided by local authorities? Well, Local Authorities have a duty to carry out an assessment of a person's needs where they appear to be in need of community care services, and a duty to provide services or support that are designed to meet those assessed needs. Local Authorities cannot commission services that are clearly the responsibility of the NHS, such as care provided by registered nurses.

So what healthcare services are Local Authorities allowed to provide? Social Services can commission care in care homes where the person's needs are *primary* social care needs but may also include elements of 'general nursing' provided by care assistants. This is where the terminology becomes jargonistic and confusing. The 'general nursing' care must be *incidental* and *ancillary* to the person's accommodation and of a *nature* that a local authority can be expected to provide.

This means that when it comes to deciding whether a person's overall needs are either *primarily* health needs that must be provided by the NHS or just *incidental/ancillary* health needs which can be provided by social services, the only 'bar' that can move is the lower limits of the NHS. This creates a certain degree of confusion and inconsistency when it comes to applying continuing healthcare eligibility criteria. It also means that if you are convinced that you have a primary health need it is worth pursuing an appeal, because a review panel may have a different professional opinion as to where the line is drawn, and that may work in your favour.

The Background to Continuing Healthcare

In the early 1990s a growing number of people found themselves paying for long-term care which had previously been provided free by the NHS or their Local Authority. Means testing was introduced for Local Authority care through the Community Care Act and subsequently the line between social or personal needs and health needs became blurred. Increasingly, the care costs for people with complex needs were being funded privately by people whose care should have been funded and managed by the NHS.

In the following years, a number of changes were introduced to the health and social care system which we've summarised for you:

- **1996** – Department of Health provides guidance to England's 95 Health Authorities to write the first sets of criteria on NHS Continuing Healthcare eligibility.
- **1999** – Pamela Coughlan wins a landmark appeal case against a ruling that she was ineligible for continuing healthcare funding. Following the Court of Appeal decision, the Department of Health instructed all Health Authorities to review their criteria to ensure it was 'Coughlan compliant'.

- **2002** – NHS undergoes reorganisation. 95 Health Authorities are abolished and replaced with 28 Strategic Health Authorities (SHAs). Department of Health issues further instruction to all SHAs to agree upon a set criteria within each area.
- **2002** – Following an investigation into NHS continuing healthcare by the Health Service Ombudsman, the Department of Health again instructs all 28 SHAs to review their criteria and bring it in line with the Coughlan judgement. They were also asked to retrospectively review everyone who had been in receipt of long-term nursing care since April 1996, providing compensation where the criteria had been applied restrictively.
- **2004** – Each SHA in England was working to its own set of criteria and toolkits which led to what became known as the ‘postcode lottery’, where eligibility was partly dependent upon where you lived. This problem is recognised by the Department of Health and in 2004, they begin developing a national set of tools and assessment processes to clarify key areas of contention.
- **2006** – A further NHS reorganisation sees the 28 Strategic Health Authorities merged into just 10, as well as a significant reduction in the number of Primary Care Trusts (PCTs).
- **2007** – *National Framework for NHS Continuing Healthcare and NHS-Funded Nursing Care* is launched. All NHS trusts are instructed to fully implement the Framework by October. Within a few years the number of people eligible for continuing healthcare doubles as a direct result of the National Framework.
- **2009** – Department of Health issues a revised National Framework in July, following wide consultation since initial launch
- **2012** – Department of Health issues a revised National Framework in November. The main purpose of the latest revision is to bring terminology in line with the pending restructuring of the NHS and to incorporate the Department of Health’s 2010 Practice Guidance into the Framework.
- **2013** – Primary Care Trusts are replaced with a greater number of Clinical Commissioning Groups (CCGs). CCGs are now responsible for implementing the National Framework with the NHS Commissioning Board replacing the role of Strategic Health Authorities in commissioning responsibilities and reviewing eligibility decisions.

A common misconception is that the “criteria for continuing healthcare has changed since 2007”. This is an excuse we have heard numerous times from professionals to justify people suddenly dropping out of eligibility at their annual review when assessments reflect no significant change in their care needs. It is important to note that despite the two revisions to the National Framework in 2009 and 2012, the **criteria for eligibility have not changed**. Instead, the revisions made small adjustments to the toolkits and assessment processes.

Things You Need to Know:

Continuing Healthcare is Not Just for Nursing Home Residents

Continuing healthcare is not restricted to any particular setting and can be received anywhere, including in your own home. This principle was clarified by case law in 2003 during the retrospective review process. Some Strategic Health Authorities at the time had been rejecting requests for review from residents of care homes without nursing before this point was clarified.

Although far fewer continuing healthcare assessments are carried out for people in care homes *without* nursing than care homes *with* nursing, assessments must be based on the individual’s assessed care needs, regardless of where that care is delivered or whether the setting is appropriate. Our experience has shown that some assessment teams still struggle to apply this important principle.

If you receive continuing healthcare in your own home the NHS must pay all costs related to your assessed health and social care needs, but it does not have to pay your rent, mortgage, food or usual utility bills. In certain situations it may be appropriate for the NHS to pay a contribution toward your utility bills if, for example, you need to run specialised equipment in order to meet your care needs.

Continuing Healthcare is Not for Life

Continuing healthcare is based on an assessment of care needs and how those needs should be met rather than on a specific diagnosis, meaning it is common for these needs to change over time. For this reason if you have been assessed as eligible for continuing healthcare, you can expect your needs to be reviewed 3 months from the original decision and annually thereafter.

This does mean that it is possible for individuals to 'drop out' of NHS funding at a later stage despite presenting with very similar needs. A typical example of this is where someone with dementia who is able to self-mobilise and presents with challenging behaviour which requires constant monitoring, is then immobilised by a fall or stroke. In that situation although the diagnosis (dementia) has not changed and in fact the person's health has worsened, the management of their needs has become less intense and therefore, the person is assessed as no longer having a primary health need.

This type of scenario is obviously one that many people struggle to accept, and there is a growing campaign amongst charities and patient groups that people with degenerative conditions should not be made to have their eligibility status reviewed.

TOP TIP

If you are in situation whereby eligibility for continuing healthcare is being withdrawn, it is important that you request a thorough explanation in writing from your Clinical Commissioning Group as to why they believe you are no longer eligible. If you disagree, you can challenge that decision.

Having a Diagnosis of Dementia Does Not Guarantee You Will be Eligible

Eligibility for continuing healthcare is not dependent upon a diagnosis, and so a person who has been diagnosed with Alzheimer's disease, Parkinson's disease or another degenerative condition will not necessarily be assessed as having a primary health need. Eligibility is determined by assessing your day-to-day care needs and how those needs should be met.

Depending on the progression of the illness a person with dementia or any other disability or illness will present with a number of health and social care needs, some of which may well be intense, complex and/or unpredictable. If any one particular health need or a combination of those needs are assessed as being of an intensity, complexity or level of unpredictability that means their *primary need is for health*, then they will be eligible for continuing healthcare.

Nobody Can be Certain That You Will be Eligible Before an Assessment has Taken Place

We frequently hear of false promises being made to people about their chances of eligibility or otherwise by health and social care professionals such as GPs and consultants who do not properly understand the continuing healthcare criteria. Attitudes toward continuing healthcare in the medical community vary greatly – many see it as an unnecessary administrative burden and some GPs simply refuse to take part in it at all. Unless the professional has spent time working within the dedicated field of NHS continuing healthcare it is unlikely they will fully understand it.

Eligibility is based upon the presence of a primary health need which is established through an in-depth assessment process during which a multidisciplinary team assesses the totality of your needs. Until this process has taken place nobody can unilaterally decide that an individual will or will not be eligible, even your GP.

Decisions Must Never be Influenced by Budgets

According to the 1946 NHS Act, nursing care in England must be provided free at the point of delivery. This means that if your needs have been assessed as primarily health needs by law, then the NHS must pay the full cost of your health and social care and accommodation. NHS continuing healthcare is not means tested and financial considerations must not be taken into account. Coordinating assessors should not ask you questions about your financial situation and if they do, you do not have to answer them because they do not need that information in order to assess your needs. Likewise a person's continuing healthcare status should be established *before* means tested social care is considered.

The National Framework is absolutely clear about this issue and makes provisions to ensure that decisions regarding eligibility are free from budgetary and commissioner influences. Beacon's caseworkers have dealt with cases in the past where commissioner influence on decision-making panels had clearly occurred. In each case our challenge to this procedural failure was upheld and the assessment process started again.

Since the implementation of the National Framework in 2007 we have tracked changes in the way in which the eligibility criteria have been interpreted. It is common for Clinical Commissioning Groups (previously PCTs) to review the way in which their assessment teams are interpreting and applying the criteria from time to time and to make changes in an effort to bring decisions in line with what they feel to be a more accurate interpretation of the guidance. However, one of the problems with the National Framework – like the 28 sets of criteria before it – is that the lack of clear definition of a primary health need, coupled with the multidisciplinary approach, leaves wide room for differing interpretations of the criteria.

This leaves the NHS open to accusations that whilst the criteria itself has not changed, the way in which it is applied has changed significantly in conjunction with the economic climate. Whilst we would not say that the economic climate impacts directly upon eligibility decisions, we certainly have plenty of evidence that points to significant differences in the way the criteria have been applied over a period of time within the same NHS trusts.

If You are Eligible for Continuing Healthcare Your Benefits May be Affected

Some benefits will change when you become eligible for continuing healthcare. If you receive Attendance Allowance (AA) or Disability Living Allowance (DLA) in a care home with nursing, these will normally stop 28 days after continuing healthcare begins, however DLA will not normally stop if you are not receiving care from a qualified nurse or if you receive care in your own home. If DLA is stopped, the DLA higher rate mobility component will continue to be paid over to Motability's service providers in relation to a hire purchase or contract hire of a 'Motability' vehicle, where relevant. If AA or DLA benefits stop, other disability-related premiums may also be affected.

TOP TIP

If you are in receipt of either AA or DLA when you become eligible for continuing healthcare it is advisable to contact the AA and DLA units on 08457 123456 to inform them of the change.

Stage 1 of the Assessment Process (Screening Checklist)

Summary of the Whole Assessment Process

For most people the first step in the assessment process is a screening stage where a nurse, doctor, social worker or other qualified healthcare professional will evaluate your needs against a Checklist tool.

The Checklist tool threshold is set intentionally low. If the Checklist indicates that you may have sufficient needs to qualify for continuing healthcare, then a full assessment will be coordinated by

your local Clinical Commissioning Group (CCG). If it is evident that you are likely to require a full assessment of need then your CCG may decide not to proceed with a Checklist and instead go straight to the full assessment stage.

There are certain circumstances under which an assessment for NHS Continuing Healthcare should be automatically triggered. These include:

- When the person is ready for discharge from hospital **prior** to a local authority funding assessment
- When going into a care home with nursing **before** receiving an NHS funded nursing care assessment
- When a person's physical or mental health appears to decline significantly

You can also seek an assessment from a health or social care professional, such as your GP or social worker, at any time. If you are unsuccessful at the assessment stages, there are a range of dispute resolution options available to you.

The second stage is a full assessment of needs. A full assessment will be completed by a multidisciplinary team, many of whom hold roles relevant to the type of care or health needs of the person undergoing assessment, and in most cases this team will comprise of health and social care professionals who have been directly involved in delivering the person's care.

The multidisciplinary team will be coordinated by a representative of the CCG (the coordinating assessor) who will use a Decision Support Tool to help the team understand the totality of your health and social needs, as well as the care required to meet those needs. The multidisciplinary team make a recommendation to the CCG as to whether or not the person in question meets the eligibility criteria and it is the role of the CCG to make a final decision. The CCG may decide to use a panel to ratify the multidisciplinary team's recommendation. Whatever the decision, the person in question should receive a letter from the CCG explaining how the decision was reached.

How to Request an Assessment

For most people the starting point will be to request a screening Checklist which is the first stage of the assessment process. If you feel that you or your relative/friend needs an assessment for continuing healthcare you should ask your GP, social worker, district nurse, care home nurse or other health professional for a Checklist assessment. This is the first stage of the assessment process and all the professionals listed above are qualified to complete the paperwork, however not all of them will be familiar with continuing healthcare procedures. It is important not to be put off having a Checklist completed by a professional who either does not understand the assessment process or does not understand the criteria and thinks that you are wasting your time. An alternative method is to contact your Clinical Commissioning Group's (CCG) continuing healthcare department to request an assessment. You can find contact details for your CCG by searching for 'services near you' at www.nhs.uk. The Checklist outcome should be forwarded to the appropriate CCG and if it indicates that you meet the criteria for a full assessment, you will be automatically referred.

In theory you should also be referred for a *Checklist* assessment automatically if your health deteriorates to the point where an assessment is necessary and your care is being overseen by a health or social care professional. This does not always happen though and people do sometimes slip through the net, particularly where people are funding their own care.

TOP TIP

If you are self-funding a care package in your home or in a care home and you do not know if a continuing healthcare Checklist has been carried out, ask the care staff, your GP or District Nurse to complete one for you.

Fast Track Assessments

People who have a rapidly deteriorating condition and are approaching the end of their lives (referred to by clinicians as entering a 'terminal phase') may need an urgent decision to be made about their

eligibility for continuing healthcare so that a care package can be arranged as soon as possible. In that situation the Fast Track Tool should be used by an appropriate clinician such as a GP, hospital consultant or district nurse who needs to outline the reasons for the Fast Track decision, supported by a prognosis (where possible) and send that information to the Clinical Commissioning Group.

Where a recommendation has been made appropriately, the CCG will work with the individual's multidisciplinary team to arrange an urgent package of care or an appropriate placement into a care home to support the preferred choice for end of life care delivery when possible.

Your Involvement in the Checklist Assessment

People who receive a Checklist assessment should be supported to play a full role in the assessment process. You and/or your representative should be given reasonable notice that the Checklist tool is to be completed so that you can arrange for a family member or representative to support you during its completion.

Your consent should be sought and recorded before the assessment takes place and the purpose of the Checklist should be explained so that you understand what is happening. People who choose not to give their consent may then miss out on Local Authority-funded care if the Local Authority consider that the care may be the responsibility of the NHS.

If the person in question does not have capacity to give their consent (an example may be a person suffering with an advanced form of dementia) the health or social care professional completing the Checklist should check to see whether you have appointed someone to have Lasting Power of Attorney on welfare matters on your behalf, or whether someone has been appointed by the Court of Protection as a personal welfare deputy for you. It is a common misconception that a spouse or other close relative can give consent on your behalf without having been formally appointed.

TOP TIP

We strongly recommend that people who are suffering with the early stages of a degenerative condition and are likely to lose capacity to make decisions regarding their finances and welfare, consider appointing a trusted relative or friend to have Lasting Power of Attorney whilst they are still able to provide consent.

If the person has not set up a Lasting Power of Attorney and nobody has been appointed as personal welfare deputy, then the health and social care professionals responsible for the person's care will be responsible for making a 'best interest' decision as to whether it is appropriate to proceed with the Checklist assessment. In making this decision, they should consult with those individuals who have a genuine interest in your welfare, such as close relatives or friends.

After a Checklist has been completed the outcome should be communicated to you (or your representative where appropriate) in writing with a rationale for how the decision was reached. If the decision is not to proceed with a full assessment the letter should contain details about how to ask the CCG to reconsider its decision.

Despite these clear procedures, we are aware that often hospital patients and their families are not told that a Checklist is to be completed or even informed of the outcome. Experience has taught us that this is usually because the health or social care professional completing the Checklist does not understand continuing healthcare procedures and is unaware of the need to involve the patient or their next of kin.

TOP TIP

If you are in hospital awaiting discharge to a care home or back to your own home with a care package, ask the hospital staff for a continuing healthcare Checklist to be completed.

TOP TIP

If somebody you have been appointed to act for is awaiting discharge from hospital into a care setting, ask the hospital staff whether a continuing healthcare Checklist has been completed. If it has, you have the right to see the outcome and ask for a review if you disagree with it.

Checklists Completed in Care Homes

If you are receiving care in a *nursing* home then you must be screened for continuing healthcare *before* an NHS-Funded Nursing Care assessment takes place. If you are receiving ongoing care in your own home, in a care home without nursing or in any other setting, you can still request a Checklist assessment from a health or social care professional and this request should be actioned.

CCGs will have different local procedures concerning their preferred Checklist completion method. Some will be happy to allow care homes to complete their own whilst others will have specially trained care professionals working in the community or attached to the CCG's continuing healthcare team who will visit the care home and complete the assessment. Either way, under the National Framework any health and social care professional is able to complete and submit a Checklist assessment to the CCG.

Health and social care professionals – including care home nurses – do not have the right to refuse to carry out a Checklist or refuse to make a referral to the CCG for a Checklist to be completed, regardless of their opinions on your eligibility.

Eligibility is based upon the presence of a primary health need which is established through an in-depth assessment process in which a multidisciplinary team fully assesses the totality of your needs. Until this detailed process has taken place, nobody can unilaterally decide that you will or will not be eligible.

Applying the Checklist

The Checklist threshold is set intentionally low in order to screen people in rather than out. It uses 11 of the care domains found in the Decision Support Tool (see *Stage 2 of the Assessment Process*) to organise an individual's needs but instead of containing between 4 and 6 descriptions of need in each domain, it contains 3. These relate to the High, Moderate, and Low/No needs descriptors in the Decision Support Tool. These 3 descriptors are assigned a letter 'A', 'B' or 'C' with 'C' being the least intense description and 'A' being most intense.

A full assessment will be required if you are assessed with any of the following:

- Two or more domains with an 'A' descriptor selected
- Five or more domains with a 'B' descriptor selected or one 'A' and four 'Bs'
- An 'A' descriptor selected in any of these domains: Behaviour, Breathing, Drug therapies and Medication, and Altered States of Consciousness

You do not necessarily *have* to meet this criteria in order to be offered a full assessment, some people may be offered an assessment with (for example) only four 'Bs' at the discretion of the CCG. Likewise it is not always necessary to complete a Checklist, the CCG may decide to carry out a full assessment without the need for a Checklist if they believe there is a reasonable chance that you may be eligible. Eligibility for a full assessment does not necessarily mean that you will end up being eligible for continuing healthcare.

The Checklist outcome should be forwarded to the appropriate CCG along with supporting information (such as risk assessments or care plans) and if it indicates that you meet the criteria for a full assessment, you will be automatically referred. Regardless of whether or not you are eligible for the full assessment, you should receive a decision letter which explains the outcome of your Checklist assessment and your rights to challenge that decision.

TOP TIP

If you are aware that a Checklist assessment has taken place but you have not received the outcome, contact the health and social care professional who completed the Checklist or your CCG to request an outcome letter.

What If I Disagree with the Checklist Decision?

If you meet any of the criteria in the previous section, you must be referred for a full assessment of need. We have come across various situations in the past in which Checklist procedures have been misapplied which has resulted in people being refused full assessments unreasonably. CCGs cannot refuse a full assessment if you have met the Checklist criteria simply because they still don't believe that you are likely to be eligible for continuing healthcare. The Checklist is designed to screen people in rather than out and the National Framework is clear - if you meet the criteria for a full assessment, the CCG must carry out a full assessment.

Checklists are often completed by hospital, care home or community health professionals rather than members of the continuing healthcare team. Depending on the quality and substance of the Checklist, it is not uncommon for CCGs to 're-screen' a Checklist assessment if they feel it is inaccurate. To avoid this, it is best to try and ensure that the Checklist is completed as accurately as possible and backed up with supporting evidence from your recent care records, such as care plans.

If the CCG have altered the Checklist so that you no longer qualify for a full assessment they must provide you with a written explanation about how the decision was reached so that you are able to understand exactly where the difference of opinion lies. If you disagree with the CCG, you have the right to formally request a reconsideration of the decision and then to access the NHS complaints procedure. At Beacon we have successfully challenged a number of inaccurate Checklist assessments.

If you have been legitimately refused a full assessment because you do not meet the Checklist criteria but you feel that this decision is incorrect, please see our *Guide to Continuing Healthcare Appeals* for practical advice on how to challenge the decision.

Stage 2 of the Assessment Process (Full Assessment of Need)

How to Request a Full Assessment of Need

If you have already had a Checklist completed which indicated that you were eligible for a full assessment, your CCG should appoint a coordinating assessor to begin the full assessment process. If you have been refused a full assessment because you do not meet the Checklist criteria and wish to challenge that decision, please see our *Guide to Continuing Healthcare Appeals*. If you have not yet had a Checklist assessment, this is the first stage in the continuing healthcare assessment process for most people. Please see the section *Stage 1 of the Assessment Process (Screening Checklist)*, above.

Good communication and consistency in the application of continuing healthcare procedures is not always evident, leaving some people completely unsure about whether they have ever been assessed for Funded Nursing Care or continuing healthcare.

TOP TIP

If you are unsure of your continuing healthcare assessment history (including NHS-Funded Nursing Care, Checklist assessments and full assessments) your CCG's continuing healthcare department should hold records of all such assessments and you can ask them for this information. You can find contact details for your CCG by searching for 'services near you' at www.nhs.uk.

Timescales for Assessment

The period of time between the Checklist referral for full assessment and a final decision regarding eligibility should not normally exceed 28 days. However, in over 10 years of dealing with continuing healthcare appeals less than 5% of the assessments we have seen have been completed within this timescale. The majority have taken on average 3 months to complete and some much longer. Since the closedown process began in 2012 (see section *what is the closedown process, below*) we have seen evidence that assessment timescales are slipping even further, with some people having to wait 6-12

months for a full assessment following a Checklist referral. Whilst we recognise the pressures on the NHS brought about by the closedown process, these timescales for new 'current' continuing healthcare assessments are simply unacceptable.

If, following the full assessment of need you are eligible for continuing healthcare, CCGs are required to backdate funding to the date of referral for a full assessment (following a Checklist decision). Under the (NHS) Refunds Guidance, March 2010, CCGs are also obliged to refund to individuals who have been assessed as eligible the full costs of care from day 29 of the receipt of a completed Checklist.

TOP TIP

If the 28 day timescale has been exceeded we would recommend that you contact your coordinating assessor or local CCG and ask them to specify clear timescales for a decision regarding eligibility, reminding them of their obligation to complete assessments within 28 days of the Checklist referral. If this timescale is still unacceptably lengthy, we recommend that you make a formal complaint against the CCG through the NHS complaint procedure. If you are unhappy with the final decision regarding eligibility for continuing healthcare and decide to appeal, you can raise the issue of lengthy timescales with the Independent Review Panel as a procedural complaint.

The Full Assessment Process

Your Clinical Commissioning Group (CCG) will appoint a *coordinating assessor* to bring together a *multidisciplinary team* (MDT) of health and social care professionals to assess your needs. The coordinating assessor will also make contact with the person being assessed or their representative to invite them to the multidisciplinary assessment meeting.

Led by the coordinating assessor, this multidisciplinary team (MDT) will use a *Decision Support Tool* (DST) to organise the evidence relating to your needs into categories. The DST contains 12 generic areas of need or 'care domains' with each care domain containing a number of levels of needs and corresponding descriptors to help the MDT assess the severity of a particular area of care.

The 12 care domains are:

Behaviour	Continence
Cognition	Skin and Tissue Viability
Psychological and Emotional Needs	Breathing
Communication	Drug Therapies and Medication: Symptom Control
Mobility	Altered States of Consciousness
Nutrition – Food and Drink	Other Significant Care Needs

The evidence that is used to populate the DST will be taken from your recent social, medical and care records and may include care plans, hospital records, social care records, GP records, daily care records, medication charts, risk assessments and any assessments from specialists such as a Speech and Language Therapist or the Mental Health team. In short, any written or verbal information relating to your needs within the assessment period should be summarised in the DST so that the multidisciplinary team (MDT) are able to make a fully informed recommendation about your eligibility for continuing healthcare. Financial records should not be included because eligibility for continuing healthcare is not means tested and should be free from financial influences.

The multidisciplinary team will then use this evidence to assign a *level of need* ranging from 'No Needs' to 'Priority', depending on the severity of that need. For example, in the *behaviour domain*, if a person is fully compliant with their care they may be assessed as having 'No Needs', whereas a person who presents with challenging or aggressive behaviour on a regular basis may be assessed as having a 'Moderate', 'High' or even 'Severe' need. Each level of need has a descriptor to help the multidisciplinary team (MDT) identify the correct level to apply.

When all 12 domains have been populated, the multidisciplinary team must decide whether the person has sufficiently *intense, complex or unpredictable* needs, as well as determining the *nature* of those

needs (known as the four 'key indicators'). At the completion of the assessment the multidisciplinary team will make a recommendation to the CCG as to whether there is a *primary health need* and therefore, if the individual is eligible for continuing healthcare.

The CCG will then make a final decision which must uphold the recommendation of the multidisciplinary team in all but exceptional circumstances. If you are successful in your assessment, NHS continuing healthcare funding will be awarded and paid from the date of the initial Checklist referral.

The CCG's Relationship with the Multidisciplinary Team

The National Framework clearly specifies that the multidisciplinary team (MDT) make a recommendation as to whether or not you meet the eligibility criteria for continuing healthcare and that the multidisciplinary team should comprise of health and social care professionals who are knowledgeable about your needs. This implies that all such professionals who are currently or have recently been involved in your care should be involved in the assessment and also involved in making a recommendation.

The CCG has certain rights regarding the MDT. For example, the role of the coordinating assessor includes providing guidance to the MDT regarding the criteria and assessment procedures. The CCG may also use a panel to ensure consistency in MDT recommendations and provide general continuing healthcare training to health and social care teams where required. If the CCG feel some health and social care professionals do not understand the criteria, it is their job (through the coordinating assessor) to guide the MDT.

The CCG does *not* have a remit to pick and choose the members of the MDT it wants to take part in the recommendation because to do so would mean that the assessment did not contain an MDT recommendation from all health and social care professionals who are knowledgeable about the person's needs. Neither can the CCG instruct an MDT to change their recommendation, even if they disagree with it when presented with the same evidence.

The Final Eligibility Decision

For most people it is the responsibility of the Clinical Commissioning Group to make a final decision as to whether you have a primary health need and meet the eligibility criteria for continuing healthcare. However CCGs should accept the recommendation of the *multidisciplinary team* in all but exceptional circumstances. Exceptional circumstances are not clearly defined but the implication is that this is where a quick decision is required. Some CCGs choose to use a panel to help them make the final decision but panels should also accept the recommendation of the multidisciplinary team in all but exceptional circumstances.

The NHS Commissioning Board is responsible for making eligibility decisions and commissioning services for prisoners and military personnel.

More About the Coordinating Assessor

The role of the coordinating assessor is to bring together the appropriate multidisciplinary team (MDT) to assess your needs and then use the information supplied by the MDT to complete the Decision Support Tool. It is also up to the coordinating assessor to ensure that you and/or your representative are involved in each stage of the process, helping you contribute as fully as possible. The coordinating assessor needs to be knowledgeable about the continuing healthcare system so that they can advise the MDT about the criteria and procedures impartially, however the final recommendation regarding eligibility rests solely with the MDT who should be familiar with your needs.

More About the Multidisciplinary Team

The *multidisciplinary team* (MDT) are made up of health and social care professionals who are involved in your care. In the context of continuing healthcare assessments, the minimum requirement for a 'safe' MDT recommendation is two professionals from different healthcare professions, such as a care home

nurse and a GP. The National Framework makes it clear that the MDT *should* consist of at least one health and one social care professional.

The principle of MDT assessments goes even further. Ideally, the MDT who provide information for the completion of the Decision Support Tool (DST) should consist of *all* health and social care professionals who are knowledgeable about your needs. That same MDT should be involved in making a recommendation as to whether or not you are eligible for continuing healthcare.

So, although CCGs are *allowed* to only use two health professionals from different healthcare professions, strictly they should use *all* the health and social care professionals currently or recently involved in the delivery of your care.

Reviewing Your Eligibility Status

The eligibility decision, including funding status, will be reviewed after three months to ensure all health needs are being met and that the person in question is still eligible for continuing healthcare. Again, this review is organised by the coordinating assessor with your full involvement. After this, the funding will be subject to annual reviews. This does mean that it is possible for individuals to ‘drop out’ of NHS funding at a later stage despite presenting with very similar needs. You can be reviewed at any time if either you, your care team or the CCG feel that your needs have changed.

TOP TIP

If you were not eligible for continuing healthcare following either a Checklist decision or a full assessment decision and you feel that your needs have changed, you should contact your care provider or your Clinical Commissioning Group to request a new Checklist.

Your Involvement in the Full Assessment Process

The National Framework places great importance on the involvement of the person who is being assessed and/or their representative at each stage of the assessment process. The coordinating assessor should invite you to contribute to the completion of the Decision Support Tool. Often this is done in person at a multidisciplinary team meeting.

The coordinating assessor should explain the assessment process and criteria to you and you should be invited to share your views and opinions about your care needs during the completion of the Decision Support Tool. This includes having an opportunity to provide information about every care domain, to select the *level of need* you feel is correct in each domain, and to provide an overall view as to the totality of your needs.

If the multidisciplinary team disagree with a level of need you have specified in a particular domain they should discuss it with you and record your viewpoint in writing.

When the coordinating assessor has compiled all the information and evidence into the Decision Support Tool they should give you an opportunity to review it and add your ‘views of the individual’.

TOP TIP

We recommend that you use this section to talk about how your healthcare needs affect your life from a personal perspective as well as summarising your views on the practical day-to-day management of your needs by your carers.

Sometimes CCGs will invite you or your representative to attend the decision-making panel if they have one, but they are not required to do this. Once a final decision has been made by the CCG they should write to you to explain the outcome and provide a full detailed rationale. This letter should refer to the *key indicators*, demonstrating that the CCG have carefully considered the nature, intensity, complexity and unpredictability of your needs in reaching their decision. The letter should explain how you can access the dispute resolution process if you disagree with the decision.

Representatives Attending the Assessment Meeting and Contributing to the DST

If you are the appropriate representative for your relative/friend, it is highly advisable that you contribute as fully as possible to the assessment process and attending the assessment in person is a good way to ensure that you are involved from the outset. The National Framework places great importance on the involvement of the person who is being assessed and/or their representative. This is because it is recognised that the person's representative (e.g. family/friends) are often experts on the care needs of the person in question.

At Beacon we understand that families and friends can often bring highly valuable insight to an assessment – if they are carers or they have previously been involved in the care of the person being assessed, they are often able to provide the coordinating assessor with information about the 'person' which cannot be gleaned from the care records alone. This is particularly useful when it comes to helping the multidisciplinary team to understand whether a particular behaviour is out of character and a result of disability or illness.

Such information can also help the multidisciplinary team to add important detail to the information contained within care records, particularly if that relative/friend visits the person being assessed regularly or helps to care for them. Time and time again we have found the information provided by family and friends to be crucial to the success of an assessment or appeal.

TOP TIP

If you are the appropriate representative for your relative/friend make sure you know when the MDT assessment meeting is taking place and that you have been invited. Coordinating assessors should provide you with sufficient notice.

Waiting for a Continuing Healthcare Assessment in Hospital

The question of whether you should remain in hospital whilst you wait for the full continuing healthcare assessment to take place really depends on how long the assessment takes and on your specific health care needs. As a general rule, we would advise you *not* to stay in hospital once you have been deemed 'fit for discharge'.

Patients with ongoing care needs who may qualify for continuing healthcare have a right to be assessed before they are discharged from NHS or Local Authority services and start their long-term care placement. If it is thought that you may be entitled to continuing healthcare, a hospital trust cannot begin 'delayed discharge' procedures until you have been assessed and the trust has established that you are not eligible for continuing healthcare.

Assessments for continuing healthcare which take place whilst you are in an 'acute' hospital setting can be inaccurate because you may not have reached your rehabilitation potential. This means that you may have the potential to continue your recovery in the near future with further treatment or rehabilitation, and this could impact upon your ongoing care needs.

Long stays in acute hospital settings can be detrimental to your recovery because they are not designed for long-term care. Even where basic care is good, we find that patients are often unable to receive the dedicated daily rehabilitation that would be available in a more appropriate long-term care placement whilst they are in an acute setting.

For this reason some NHS trusts operate a policy whereby continuing healthcare assessments only take place once the individual has been moved out of the acute setting and into intermediate care in a community hospital, their own home or a care home.

Continuing healthcare assessments should normally be completed within 28 days although this timescale is often not met. If you have been deemed fit for discharge from hospital but you are awaiting a continuing healthcare decision and no interim care services have been arranged, it is usually advisable to move into your long-term care setting rather than insist upon waiting in hospital until the assessment

process has been completed. This avoids the further potential for the type of health issues that can occur during long periods in acute settings and if you are found to be eligible for continuing healthcare, the start date for funding can be backdated.

TOP TIP

How to Prepare for a Full Assessment

1. Thoroughly read through this guide in order to familiarise yourself with the process.
2. If you have time, read Age UK's Fact Sheet 20 (enclosed with your Navigational Toolkit) for a comprehensive summary of the National Framework.
3. Discuss the assessment in advance with your care home manager or care agency, asking them to ensure that all care plans, risk assessments and daily records are fully up to date. Ensure that they have recorded any significant incidents such as falls, seizures or episodes of very challenging behaviour.
4. If you have time, ask your care home manager or care agency for a care plan review. Use this review to check the detail and accuracy of each element of your care. Use the section *Making Sense of the Domains*, below, as a guide.
5. If there is an area of care that is particularly intense or complex or unpredictable such as challenging behaviour or management of nutrition, it may be useful to ask the care home manager or care agency to keep a detailed one-week log of all events related to that particular need in the lead up to the assessment. For example, if challenging behaviour is difficult for the care staff to manage, ask them to keep a *Cohen-Mansfield Agitation Inventory*, an *ABC chart*, or similar.
6. If you are the representative of the person who is to be assessed, keep a written record of your visits to the person in a diary, and encourage other people who visit to do the same. Each time you visit, make a short and succinct record of how the person presented physically, mentally and emotionally. Did they greet you? How did they look? Were they awake or asleep? Did you feed them a meal? If so, did they eat it and how long did it take? Were they verbally or physically aggressive at all? Did they seem agitated? Did they appear tearful or anxious? Did they communicate with you verbally or through gestures? Did you notice anything unusual? You may find it useful to refer to the section *Making Sense of the Domains*, below, as a guide.
7. Keep all of the paperwork you have been sent from the Clinical Commissioning Group relating to your continuing healthcare screening Checklist and full assessment.
8. Make a list of any questions you want to ask your coordinating assessor about the assessment process, timescales for completion, care planning, completing the Decision Support Tool or anything else you would like to know.

The Importance of Good Care Records

Continuing healthcare assessments are only as accurate as the information that is provided to inform them. They go into great detail about your day-to-day care needs and so it is very important that medical and care records are complete, accurate and detailed. Verbal evidence from you or your family/friends should be taken into account during the assessment process but greater weight is given to the written evidence that is recorded at the time.

The *National Minimum Standards for Care Homes* require the records kept by care homes to be up to date and accurate. If a care home implements a policy preventing the recording of certain types of care needs, it is not meeting the National Minimum Standards and such policies should be challenged.

Registered Nurses also subscribe to a set of standards that require them to keep clear and accurate records, which places a greater responsibility on care homes with nursing to keep good records.

Good care records will not just make generic comments but will capture your needs as those needs change and develop, they will describe each need in detail including how the need is met and how effective the treatment or management of that need is.

A set of care records should contain care plans that describe how each particular area of need affects your wellbeing and details the necessary steps required to meet that particular need. There are many ways in which one particular care need could interact with another and it is important that records reflect how each need impacts upon the person and carefully describes how their needs should be met.

TOP TIP

If records do not capture the complexity, intensity and frequency of meeting a need then that complexity or intensity will not be reflected in the continuing healthcare assessment, and since intensity and complexity are key indicators of a primary health need, poor record-keeping could be the difference between you being assessed as eligible or not.

Time and time again we see sets of records that do not in any way reflect the care events that are occurring on a daily basis, nor the ways in which needs are met. Much of our time is spent working with care homes and agencies to improve the quality of their record-keeping or to produce new and more accurate evidence to support a case. This information is crucial to an accurate assessment. For a practical guide on the type of things you should think about in each area of care, see the section *Making Sense of the Domains*, below.

What to do During the Assessment Meeting

The National Framework places great importance on the involvement of the person who is being assessed and/or their representative at each stage of the assessment process. In order for people to contribute to the assessment process in a meaningful way it is important that they understand the criteria, the toolkits and the assessment processes as fully as possible. If the coordinating assessor were to simply ask a number of questions about your care but not explain anything to you, that information may help them to complete the evidence sections for each care domain but it would not enable you to express an informed opinion as to the level of need you think should be assigned to each particular care domain, nor help you to provide a viewpoint regarding whether your needs meet the criteria.

We find that when coordinating assessors help people to understand the criteria and the processes involved in an assessment, they are in a much better place to contribute relevant evidence and information which may prove important to the assessment and overall 'picture' of the person's needs.

NHS continuing healthcare is a complex area of health policy and it is true that many people struggle to fully understand it, especially when coming into the system for the first time. Nevertheless this does not mean that coordinating assessors and CCGs should not try to help people to understand the criteria and assessment processes involved. If people are not helped to understand how the information they provide will be used, then the assessment may lack important evidence that could have come to light if the coordinating assessor had explained the criteria and assessment principles.

From experience we know that a lack of involvement by CCGs and assessment teams can lead to mistrust in the assessment process which in turn can push people into appealing a decision that otherwise they may have agreed with had they been helped to understand the criteria. In that respect it is in the interests of both the NHS and the person being assessed for the coordinating assessor to fully involve the person and/or their representative at each stage.

If you are attending the MDT assessment meeting for yourself or as the representative of the person being assessed, we recommend that you make the most of your meeting by following these steps:

1. **Contact the coordinating assessor** to confirm the date, time and location of the assessment.
2. **Follow the steps described in the section *How to Prepare for a Full Assessment***, so that the care home or care agency's records will be accurate and comprehensive.
3. **Make sure that the key member of your care team attends the meeting** (such as your key nurse) as the care home or care agency's representative. You can also ask what other members of the multidisciplinary team will be present (such as social worker, GP etc).
4. **Ask the coordinating assessor to explain how the meeting will take place** and what information they will need from you at each stage.
5. **Ask the coordinating assessor to explain the whole continuing healthcare assessment process to you** including:
 - a. how each care domain will be considered and the levels of need chosen
 - b. how you will be involved in each stage of the assessment process
 - c. how the key indicators of nature, intensity, complexity and unpredictability will be applied
 - d. what are the timescales and who will be involved at each stage
 - e. which members of your multidisciplinary team will be involved in making the recommendation regarding eligibility
 - f. will the Clinical Commissioning Team (CCG) use a panel as part of their decision-making process and are you able to attend
 - g. will you be provided with a final draft of the Decision Support Tool to comment on before it goes to the CCG for a decision
6. **Tell the coordinating assessor who has been involved in your care over the past year.** This will help to ensure that every member of your multidisciplinary team is involved in the assessment. Such professionals may include your Social Worker, hospital Consultant, GP, Speech and Language Therapist, District Nurse, Community Psychiatric Nurse, Physiotherapist, care home Nurse, Carers, etc. You can ask the care team representative at your meeting to confirm any specialist involvement you may not have thought about.
7. **Talk about care needs in detail.** The coordinating assessor should work through each of the 12 care domains in turn, asking you, your care team representative and any other member of your multidisciplinary team present at the meeting their views about your health and social care needs in each of the domains.

We recommend that you tell the coordinating assessor about anything and everything that is relevant to that particular domain, using the information in the section *Making Sense of the Domains*, below, as a guide. Please remember that however much or little you understand about health conditions, you are the expert on the person being assessed because you know them better than anybody else at the meeting. No piece of information is too insignificant so you should tell the coordinating assessor everything.

8. **Remember that this assessment is not a 'snapshot' in time** – the assessment does need to reflect your *current* needs but in order to provide a rounded view of your current needs it is good practice for the assessor to capture information from the past few months. If you have recently left hospital it is important that the assessor takes into account the development of your health and social care needs from hospital to long-term care setting.

Likewise, it is common for people's care needs to fluctuate on a daily basis, some people will be more comfortable or settled on some days than others. It is important that you tell the

coordinating assessor about how you have been in recent weeks and months, not just how you are today. For example, a person with dementia who displays agitated or aggressive behaviour may only do so a couple of times each week and be perfectly calm and cooperative the rest of the time. A 'snapshot' of the person's needs on just one day would not provide an accurate or balanced view.

9. **Try to be as realistic as possible about your day to day care needs** or those of the person you are representing. Nobody likes talking about how much they have deteriorated or about the things that they can't do any more, but it is extremely important that you try to be as realistic as possible about your needs so that the coordinating assessor is able to build up an accurate portrayal of needs in the Decision Support Tool. A useful tip is to describe your care needs as if it were the 'worst day'. If you are representing someone else and you feel that they are 'putting on a brave face', it may be appropriate to ask the coordinating assessor if you can speak to them privately after the meeting to give them what you feel is a more accurate description of the person's needs.
10. **Try to make sure that the care team representative describes your needs accurately.** From experience, some care staff (such as nurses or carers) can be cautious about being too 'negative' about a person's care needs, either because they don't want to upset the person or their family/friend in the meeting, or because they feel it will reflect badly on them. This may be because they feel that admitting they find it difficult to cope with a behaviour or a certain care function may imply that they can't cope, or admitting to falls might reflect badly on the care home's reputation. However, these concerns are often misplaced and it is more important for them to be objective and realistic.
11. **If there is anything you don't understand or would like further clarification about, just ask.** It is important that you are given every opportunity to understand what is being said and how that may impact upon the assessment. Try not to feel intimidated by your lack of medical knowledge, you have a right to understand what is happening at each stage.
12. **Have your 'level of needs' recorded in the Decision Support Tool.** After discussing each care domain, the coordinating assessor should try to achieve some consensus as to the level of need that should be applied. It is ok to disagree with them if you feel that a higher or lower level of need is more appropriate. For example, the coordinating assessor and care team representative may feel that the person's cognitive needs fit the descriptor of a Moderate level of need in the Cognition domain, whereas you may feel the High level of need is more appropriate.

You should discuss your reasons with the coordinating assessor but it is ok to disagree if you cannot find a consensus. In this situation the coordinating assessor should record your views in the Decision Support Tool. Whether you agree or disagree, always ask the coordinating assessor and any members of your multidisciplinary team present to explain their reasons for choosing a particular level of need and make sure that this fits the wording of the descriptor in that level. It may also be useful to reflect on their reasons to see if that changes your own view. If you are unsure, ask to see the Decision Support Tool so that you can read the descriptor. Remember that you cannot challenge the wording of the descriptor, but you can challenge the multidisciplinary team's interpretation of your needs.

13. **Ask the coordinating assessor to comment on the key indicators.** As you work through each care domain and assign a level of need, it is good practice to discuss the presence of the 'key indicators' of nature, intensity, complexity and unpredictability. If a Moderate, High, Severe or Priority level of need has been assigned to a particular care domain, it is very possible that the area of need the domain relates to (such as communication, mobility, continence etc) will have a level of intensity, complexity or unpredictability in the day-to-day management of that particular need. It is important that intensity, complexity and unpredictability are considered against each area of care, and when looking at the totality of your needs.

14. **Provide any written evidence you think will be useful.** After the meeting has finished, the coordinating assessor should begin the process of gathering written documentation related to your health and social care needs such as previous continuing healthcare assessments, care plans, risk assessments, daily evaluation reports, medication, hospital and GP records, and specialist assessments relevant to the weeks and months directly preceding the assessment date. You can ask the coordinating assessor what information they will be gathering and ask them to consider anything else you feel may be relevant. You should also provide them with a copy of your visitor's diary, if you are representing the person being assessed.

What to do After the Assessment Meeting

The assessment process is not closed until the Clinical Commissioning Group has made a decision regarding eligibility. If anything occurs to you after the meeting that you feel may be significant to the assessment, contact your coordinating assessor to let them know. You should also contact them if you feel that the agreed timescales for completion of the assessment have been exceeded to clarify when a decision regarding eligibility will be made. It is not uncommon for timescales to slip because coordinating assessors are waiting for information from other members of the multidisciplinary team and it may be possible for you to speed things up by contacting whoever is holding up the assessment process directly.

It is good practice for the CCG to provide you with a copy of the *draft* Decision Support Tool before they make a final decision regarding eligibility, however the CCG are not obliged to share the DST with you at this stage. Either way, it is important that you feel that you have had sufficient opportunity to talk about your care needs and to communicate your views as to why you feel you are eligible for continuing healthcare before a final decision is made by the CCG. If you are given the opportunity to comment on the draft Decision Support Tool before it goes to the CCG it may be useful for you to know the recommendation of the multidisciplinary team regarding whether or not they feel that you are eligible.

The Clinical Commissioning Group (CCG) should review the Decision Support Tool alongside the evidence that has been collated and uphold the recommendation of the multidisciplinary team in all but exceptional circumstances. They should then write to you or your representative promptly with a rationale for how the decision was made, as well as information about how to contact the CCG if you wish to challenge the eligibility decision.

When you receive this letter, we recommend that you also request a copy of the final Decision Support Tool and then use the following checklist to make certain that the process of assessment has been carried out correctly. If you cannot say 'yes' to any one of these items, you can appeal your assessment on procedural grounds:

- You or your representative were invited to attend the multidisciplinary assessment meeting.
- You or your representative were given sufficient opportunity to talk about your care needs and to communicate your views as to why you felt you were eligible for continuing healthcare.
- Your comments and views are clearly contained in the Decision Support Tool, including where you have disagreed with a level of need assigned to a care domain.
- The Decision Support Tool references all relevant evidence related to your care needs.
- The Decision Support Tool contains a list of the members of your multidisciplinary team, and this team is made up of at least two health care professionals from different disciplines.
- All the health and social care professionals currently or recently involved in meeting your care needs have had an opportunity to contribute to the assessment and Decision Support Tool.
- There is evidence in the Decision Support Tool of a genuine and meaningful discussion between the members of your multidisciplinary team about whether or not you are eligible for continuing healthcare

(Note: it is not acceptable for members of the multidisciplinary team to simply state that they 'agree with the assessment', they must provide a recommendation regarding eligibility).

- There is a clear overall recommendation as to whether or not you have a primary health need and are eligible for continuing healthcare which has been made by the multidisciplinary team (Note: it is not acceptable for the multidisciplinary team to ask a CCG or decision panel to make the recommendation on their behalf).
- The CCG and/or decision panel did not change any of the levels of need assigned to the 12 care domains by the multidisciplinary team.
- The CCG and/or decision panel agreed with the multidisciplinary team's recommendation regarding eligibility, unless there were exceptional circumstances. If they did not agree with the recommendation then there should be a clear rationale explaining the exceptional circumstances that forced them not to accept the recommendation in your decision letter (Note: CCGs and decision panels cannot come to overrule the multidisciplinary team simply because they have come to a different conclusion when presented with the same evidence).
- The decision letter clearly explains how the decision was reached and makes specific reference to how your needs meet the eligibility criteria and the key indicators of nature, intensity, complexity and unpredictability.
- There is no evidence of budgetary or commissioner influences in the assessment or decision-making process.
- The full assessment process was completed within 28 days of the Checklist referral.

Making Sense of the Domains

The 12 care domains contained within the Decision Support Tool are intended to be used to organise a person's care needs so that the nature, intensity, complexity and unpredictability of those needs can be fully understood. The information and evidence relating to each domain is used to determine a *level of need* ranging from 'No Needs' to 'Priority', depending on the severity of that need.

Much of the information used to populate the care domains will be taken from existing care records and assessments although verbal evidence which is gathered at the assessment meeting will also play an important part in populating the domains with accurate and up-to-date information about your care needs. There are many ways in which one particular care need could interact with another and it is important that care records reflect how each need impacts upon *the person* and carefully describes how needs should be met. If records do not capture the complexity, intensity and frequency of meeting a need or a combination of needs then that complexity or intensity will not be reflected in the continuing healthcare assessment.

For example, a care plan may record that a person is verbally aggressive on every care intervention and physically aggressive on average 3 times per week. If the care staff do not record this aggression *every time* it occurs because they are so used to dealing with it, a continuing healthcare decision panel may decide that the aggression is not actually as bad as the care plan claims it to be and may instead conclude that the care plan is inaccurate. This could result in the wrong decision being reached about your eligibility.

Carers, care homes and care agencies should also record a daily log of events with a summary of the needs that the person has presented with on that day, the steps that were taken to meet those needs and how effective they were. It is not enough to simply write that care was 'given as per care plan' or similar generic comments because such record keeping often misses important nuances in the person's needs that can accumulate over time and end up looking quite different to the original care plan.

It is very difficult to provide accurate guidance as to how to interpret the levels of need descriptors within the 12 care domains without over-generalising or changing their meaning, so instead we aim to provide guidance as to the types of things you should consider when it comes to deciding the correct level of need to apply in each domain. The sections below contain a summary list of the most important things we believe you need to think about during the multidisciplinary assessment meeting and whenever you are given an opportunity to share your views about the person's care needs:

1. Behaviour

- This domain relates to challenging behaviour which could be in physical, verbal or passive form. It contains six levels of need ranging from No Needs to Priority, each with a descriptor to help you identify the correct level to apply. It does not matter whether the challenging behaviour has resulted from a condition (such as dementia) or is a part of the person's character, everything should be recorded.
- Challenging behaviour is not just about aggression. Wandering, moving furniture, eating plants, invading another resident's personal space and behaviours resulting from anxiety can all be challenging for care staff to manage.
- Think about the type of behaviour the person is presenting with. Is it verbal such as shouting, swearing or screaming? Is it physical toward other people such as slapping, hitting, punching, kicking, spitting or squeezing? Is it physically destructive toward property? Is it non-aggressive physical behaviour such as deliberate silence, withdrawing from activity, restlessness or pacing? Is it socially-inappropriate behaviour such as sexual disinhibition?
- Does the behaviour put the person or other people at risk of harm? What severity of risk are other people at (for example is the risk that a carer may be scratched on the arm during personal care or is it that another resident may be slapped in the face without warning?) Are there any recorded incidents of harm to a carer or another resident or to the person themselves through their challenging behaviour?
- Try to describe any known triggers for the challenging behaviour such as a particular environment or person. Is the person more challenging around family members or around care staff? Are there times of the day in which the behaviour is more challenging or are there certain care interventions which seem to trigger the behaviour (for example changing a pad or feeding a meal?)
- How is the behaviour being managed? Are certain techniques used by care staff to reduce the behaviour such as distraction, returning at a later time to try again, a calm approach, medication, restraint or the carer explaining what they are doing at all times?
- What is the intensity and frequency of 'interventions' needed to address the behaviour and reduce risk of harm to the person or others? For example, if care staff 'retreat' from applying skin cream because the person is likely to try to hit them, how many times will they have to return before the person is calm enough to try again?
- How affective is each technique at controlling the behaviour and reducing risk of harm? Has medication made a difference?
- Are there any specialists involved in managing the person's behaviour such as a mental health nurse? Is there a care plan in place to deal with challenging behaviour?
- Experience shows that there is often disagreement as to whether a Moderate level of need or a High level of need should be applied in the behaviour domain. The care staff may be able to manage the person's challenging behaviour adequately, however no matter how effective the care staff may be in managing the behaviour, unless they are able to maintain a level of behaviour that *does not pose a risk* to anyone or anything and the person is *nearly always compliant* with care, the person should not be assigned a level of need any lower than High.

2. Cognition

- Cognition refers to the various mental processes of the brain that deal with information, working memory, comprehending language, calculating, reasoning, problem solving, and decision making. Cognitive impairment may typically affect mental abilities such as thinking, knowing and remembering. This domain contains five levels of need ranging from No Needs to Severe, each with a descriptor to help you identify the correct level to apply.
- Is there evidence of deterioration which is related to a particular condition or injury and affects cognition? It may be helpful to think about the person's character, personality and abilities prior to their diagnosis or injury so that you are able to describe the ways in which the person's ability to think, remember and reason has changed. Has the person had any recent cognitive assessments such as a Mini Mental State Examination, or involvement from the mental health team?
- Think about the following questions: has the person's ability to reason been inhibited? Are they able to concentrate? Do they recognise close relatives and friends? If they do show recognition, can they remember relative's names? Is there anything else you can say about the person's long-term memory such as their ability to remember their previous employment? Is the person able to retain information in the short term?
- How does the person respond to questions? Are they able to make even basic decisions such as what they would like to have to eat or drink if offered two options? If they were asked whether they would like to wear the red shirt/dress or the blue shirt/dress would they be able to understand the question and make a decision? Do you think they know where they are (their care environment) or what time of day it is? Are they responsive to you when you visit them or sleepy/inactive for much of the time? Assuming their eyesight is not impaired, are they able to focus their eyes on you and sustain eye contact?
- Once you have thought about the person's level of cognition, describe the risks presented by their impairment. Are they able to recognise basic risks from (for example) heat, electricity, fire or road safety? Does the person display disinhibited or sexualised behaviour? Would they think to cool down a hot cup of tea before drinking it? Do they have unrealistic expectations of their abilities (for example a person who is non weight-bearing trying to stand on their own)? Is the person able to change their own behaviour to maintain their safety?
- Is there evidence of fluctuation in the person's cognition? Does their ability to understand, choose, concentrate, respond, or follow instructions fluctuate from one day to the next or in different surroundings?
- How are the risks associated with the person's cognitive impairment managed? Do they have a relevant care plan? Is 1-2-1 supervision or a system of frequent checks necessary? How frequent are the 'planned interventions'? Does the person have medication to manage the symptoms or progression of their cognitive impairment?
- If the person has significant short and long term memory problems or disorientation to time, place or person, the next most important consideration is their ability to comprehend and respond to *basic risks*. In many cases this will be the difference between a Moderate, High or Severe level of needs. Some people with significant cognitive impairment are still able to instinctively react to danger and try to remove themselves from harm. However, if the person is *completely unable* to assess even basic risks (fire, physical abuse etc) even with assistance, being fully dependent on others to protect them, a Severe level of need may well be appropriate.

3. Psychological and Emotional Needs

- This domain was added to the Decision Support Tool at the launch of the National Framework in 2007. It contains four levels of need from No Needs to High, each with a descriptor to help you identify the correct level to apply. It is designed to help the multidisciplinary team understand how the person's psychological and emotional needs impact upon their day-to-day care needs.

- Experience has shown us that this can be a particularly difficult domain to assess, particularly if the person in question is cognitively impaired. The descriptors contain some similarities to the cognition domain descriptors, however this domain is designed to identify needs resulting from a person's psychological and emotional wellbeing, not from their cognitive impairment. For example, if the person is withdrawn from social activities, ask yourself why that is. If they are withdrawn because their dementia means that they *cannot* engage in any social activities, that need is related to cognition (the previous domain). However, if they have made a *choice* to withdraw themselves from activities due to unhappiness, depression or anxiety, that is more likely to be a psychological/emotional need.
- Do the person's psychological and emotional needs relate to a condition requiring active treatment (such as depression), or is there evidence of the need being associated to a 'circumstance' such as an upsetting diagnosis? Has the person had any involvement from a psychiatrist or psychologist? Are they currently taking medication to manage their psychological and emotional needs?
- Think carefully about the impact of any psychological conditions on the person. You will be in a better position than many to comment on how the person's psychological needs have affected their wellbeing. Think about how they presented before the psychological condition began. What has changed?
- Try to assess the impact by asking yourself these questions: Is the person anxious or tearful when you visit them? Do they have low self-esteem? Do they suffer from panic attacks? Do they show any other more subtle signs of anxiety or distress such as shaking, rubbing their clothes with their hands, pulling at clothes, tense limbs or displaying behaviour that seems out of the ordinary? Is there evidence that the person is deliberately disengaging with care planning or support, or is removing themselves from social interaction?
- Are there any risks associated with the person's psychological and emotional state? For example are they at risk of self-isolation or self-harm? Is there a care plan for management of those needs? Bear in mind that some care homes and agencies are not proactive about recording psychological needs, especially in dementia patients.
- Does the person's mood fluctuate? If so how rapidly? Is it possible to anticipate their emotional and psychological state?
- Look at whether there is evidence of any psychotic symptoms such as hallucinations, delusions, paranoia, mood disorders or frequent night terrors. How severe are the symptoms and how are they managed?
- What is the impact of the person's psychological and emotional condition on their health and wellbeing? Is it having an impact? If so to what extent? Is the impact mild or severe – the answer to this question could determine the difference between a Low, Moderate or High level of need. Does the person refuse food or care? Do they self-harm? Do they isolate themselves from other residents? Do they refuse medication? Does care intervention cause a high level of anxiety? Do they suffer panic attacks? Do hallucinations or night terrors cause distress?
- When you or a carer tries to offer reassurance, does the person respond to it? If so for how long? What type of reassurance do they respond to and how can you tell that they have responded (for example appearing visibly calmer after a period of anxiety)?

4. Communication

- Essentially, the communication domain assesses the person's ability to reliably communicate even basic information, verbally or non-verbally, with or without assistance. It does not just look at a person's ability to hold a sensible conversation. This domain is closely related to the cognition domain and the needs in one often impact on the other. The communication domain contains four levels of need ranging from No Needs to High, each with a descriptor to help you identify the correct level to apply.

- A starting point is to identify whether the person has any hearing or sight impairment that restricts their ability to communicate. If so, what equipment and/or techniques are used to aid the person's ability to communicate? How successful are they?
- Next, think about *how* the person usually communicates. Are they able to hold a conversation? Is the conversation grounded in reality or fantasy? Do they initiate communication or do they need encouragement? Can they speak in sentences? Do they have problems word-finding? Is speech muddled or non-sensical? If they cannot verbalise, are they able to communicate with single words such as 'hot' or 'cold'?
- If they cannot communicate at all verbally, are they able to do so with non-verbal communication. This can be as obvious as a nod or shake of the head to indicate their preference, or as subtle as a smile or small gesture. Do they show any signs that they are able to process the information given to them?
- Then consider *what* the person is able to communicate. Can they express opinions about their care and make their views known clearly, either verbally or non-verbally? If not, are they able to communicate *basic* needs such as being too hot or cold, being thirsty or needing the toilet? This may be as subtle as touching their lips to indicate thirst to a carer who is familiar with their needs and can 'read the signs' to anticipate their needs.
- Reliability is a key consideration when it comes to communication. Even if the person is able to communicate very basic needs to care staff, is that communication *reliable*? A good way to test this is to think about whether, if the person were asked if they wanted a cup of tea or glass of water and they nodded or said 'yes', would they actually drink it or leave it? Also, if given the choice of two items of clothing and the person points to one, is that a *reliable* indication of their preference or just an instinctive reaction?
- Where there is some doubt as to a person's ability to reliably communicate basic needs verbally or non-verbally a good test is to consider whether they are able to summon help in an emergency or make it known that they are experiencing pain. If a person cannot reliably communicate even with a gesture that they are experiencing pain, then it is usually reasonable to conclude that a High level of need is appropriate.

5. Mobility

- There are two common misconceptions about the mobility domain. The first is that being unable to walk means the same thing as complete immobility. There are, in fact, different levels of immobility, and complete immobility not only refers to an inability to weight-bear but also being unable to move your limbs. The second misconception is that the highest mobility need a person can present with is immobility. In fact the domain descriptors allow for a greater level of mobility needs in addition to complete immobility which impact upon the intensity or complexity of meeting a person's mobility needs. These include involuntary spasms, contractures and physical conditions requiring critical positioning, without which the person would be at high risk of serious physical harm.
- The mobility domain contains five levels of need ranging from No Needs to Severe, each with a descriptor to help you identify the correct level to apply. Think about the person's ability to stand and transfer to a different room, for example going from their bedroom to the lounge. Does the person weight-bear? Can they walk unaided or do they need assistance? If they need assistance, how many carers are required? Is their weight-bearing ability consistent or are they sometimes unable to? Can they stand on their own? Do they use a mobility aid?
- Is there a moving and handling care plan that describes the *transfers process*? A good care plan will describe the process in detail. If the person is non weight-bearing what type of hoist is required? Does the person require a certain approach or a third member of staff to keep them calm during transfers? Are they likely to attempt to mobilise and require careful monitoring to ensure their safety? Do they suffer from stiff or contracted limbs which require careful positioning? Are they able to assist or cooperate or do they actively resist? Are they likely to become aggressive during transfers? Does lack

of muscle tone result in a lean to one side which could result in a fall? The care plan should capture the person's specific set of mobility needs and describe the actual *process* of moving and handling.

- Is there a falls risk assessment? Does the risk assessment identify a likelihood of falls? Have any recent falls been recorded? Is there a history of falls or of the person being 'found on the floor'? What steps are care staff taking to manage the risk of falls? The mobility domain descriptors talk about moderate and high risks of falls, as evidenced in risk assessments or falls histories. Many people using mobility aids and adaptations will have a moderate or high risk of falls recorded in their risk assessment but may not have *actually* fallen. Clinical Commissioning Groups may try to argue that the risk entry is just procedural and that the person is not actually at risk unless there is evidence that they have fallen in the recent past. We would advise you to be clear about how you perceive the risks and ensure that entries in risk assessments are not just dismissed by the coordinating assessor if the risk of falling is genuine, regardless of whether or not they have *actually* fallen.
- Also think about whether the person has any other complicating physical needs impacting upon their mobility. What is their body posture like? Do they have any weakness following a stroke? Which side is the weakness? Does the person need to be supported by pillows? Do they slide down the bed or chair? Are they in a specialist chair due to poor posture? How frequently do they need turning (in bed) or repositioning (in a chair) to keep them safe and comfortable? This all impacts upon the intensity and complexity of meeting the person's mobility needs.
- Finally, think about the person's ability to move. Is their movement restricted by stiff or contracted limbs? Can those limbs be moved at all or would that be too painful? Does the person have any involuntary movements or spasms? How does the physical restriction impact on the care staff's ability to wash, dress and carry out personal care? What is the effect of these needs on the person's daily living?

6. Nutrition

- The nutrition domain covers everything involved in meeting the person's nutritional requirements. It contains five levels of need ranging from No Needs to Severe, each with a descriptor to help you identify the correct level to apply.
- Start off by thinking about the person's ability to eat and drink. Are they able to eat and drink independently or do they need assistance? If they need assistance, is this just prompting and encouragement or do they need a carer to be present the whole time to feed them? How long does it usually take the person to finish a whole meal? If the person needs feeding and typically takes longer than half an hour to complete a meal they have at least a Moderate level of need.
- Next, consider the person's appetite. Do they have a good appetite and fluid intake? Do they refuse meals or drinks? Are they so preoccupied by wandering (for example) that care staff find it difficult to get them to stay still long enough to eat? Do they have a recognised eating disorder? It may be useful to look at nutrition/fluid intake or output charts. Many care homes will record the intake of meals on a daily basis.
- Having considered the person's appetite, now think about the impact this has on their weight and 'nutritional status'. Is the person overweight or underweight? What is their Body Mass Index (BMI) and is this within the 'healthy range' of 18.5-24.9? If not, does the person require supplements or high-calorie food, or another form of diet management? Has the person experienced significant weight gain or weight loss that does not appear to be directly related to their nutritional intake and could indicate an underlying condition?
- Consider whether the person presents with any physical deterioration that may have an impact on their ability to eat and drink. Does the person have a 'compromised swallow' or a diagnosis of dysphagia? Are they at risk of choking or 'aspiration'? Does the person require thickener in their drinks to aid their swallow? Do meals need to be softened, liquidised or pureed (note that there is a difference between

these)? Does the person suffer with gastric reflux? Do they have a behavioural need that impacts upon their nutrition such as 'pouching' food in their mouth?

- Has the person received any input from a Speech and Language Therapist or Nutritionist? If so, what were their recommendations? How recently were they involved and are they actively monitoring the person's nutritional status? Are special techniques or equipment required in order to safely feed the person?
- Does the person require artificial feeding through a PEG or NG tube? Is the PEG well tolerated or problematic? Have there been any episodes of reflux, nausea or vomiting which may indicate a problematic PEG?

7. Continence

- The continence domain has four levels of need ranging from No Needs to High, each with a descriptor to help you identify the correct level to apply. Continence needs are often quite well described within the care home or care agency's elimination care plans and so care staff should be in a better place than many relatives and friends to describe the person's continence needs. Nevertheless, it is important to check that those needs are discussed fully at the multidisciplinary assessment meeting.
- Is the person incontinent of urine or faeces or are they able to maintain full control over their bowel and bladder? Is their incontinence double or only urinary? Is their incontinence occasional or all of the time? How long have they been incontinent? Has the person received any planned 'investigations'? If the person is doubly incontinent but the management of their continence is routine they would usually be assessed as having a Moderate level of need. The High level of need is applied in situations where the management of a person's continence is problematic and beyond what could be described as 'routine'.
- How is their incontinence managed? This may be through the use of pads, a catheter or a penile sheath for example, or it may just be managed through regular toileting. How frequently do pads need to be changed? Is the catheter problematic (including problems with the catheter 'site' or episodes of 'retention')? How frequently do care staff need to intervene over a 24 hour period in order to safely manage the person's continence?
- Has the person experienced any urinary tract infections (UTI) recently or do they have a history of UTIs? Have they suffered any bowel infections? If so, how frequently and how were these infections managed (for example through a course of medication)? Does the person experience constipation regularly, possibly requiring medication?
- Finally, are there any behavioural needs that impact upon the person's continence care. This may include, for example, pulling out the catheter and requiring frequent re-catheterisation or tearing up pads.

8. Skin

- The skin domain has five levels of need ranging from No Needs to Severe, each with a descriptor to help you identify the correct level to apply. There are multiple types of skin needs and conditions that can be attributed to the skin domain, and experience shows that skin needs tend to impact on a range of other domains. Because of this it may be useful to start by thinking about how the person's mobility, continence and weight impacts upon their 'skin integrity'.
- Find out whether the person has had a pressure ulcer risk assessment completed such as a 'Waterlow' or similar. Do they have a care plan in place for the management of their skin integrity? Has the person been assessed as being at medium or high risk of skin breakdown? (Note that a Waterlow score indicating high risk of breakdown does not necessarily equate to a High level of need in the skin domain).
- What are the person's skin needs? Are they nursed in bed and if so how frequently do they require turning to prevent skin breakdown in the day and at night? How many care staff are required to safely turn them and to carry out other elements of personal care such as washing (bed baths)? Do they

need periods of bed rest for pressure relief? If they are in a chair for most of the day but unable to reposition themselves, how frequently do they require repositioning?

- Describe the current condition of the person's skin. Is it like 'tissue paper'? Is it broken, bruised, grazed or sore in any areas? Are there any rashes? Does the person have any pressure sores/ulcers and if so what size and 'grade' are these? (This depends on the level of damage to the skin and tissue – the care staff or GP should be able to confirm this). If the person has a catheter or PEG, what is the condition of the 'site'?
- What measures have been put in place to manage the person's skin needs and prevent breakdown? Is any equipment required such as a special mattress, cushion or sling? Does the person require use of creams and if so, how often are these applied? Does the care plan specify any routines or techniques to be employed when carrying out personal care to effectively manage the risk of skin tears?
- If the person is currently suffering with a skin ulcer or tissue damage, how is the wound being managed? What dressings have been applied and how frequently are they changed? What other treatments are being used, how long have they been used for and are they proving effective (is the wound responding)? Have there been any infections in the wound? Who is responsible for monitoring the wound in the care environment? Have any specialists been involved in skin care such as a Tissue Viability Nurse or Dermatologist?
- Be aware of clinical terminology when considering the level of need you feel is appropriate to apply in the skin domain. For example, a *skin condition* is different to the *condition of the skin*. Both the Low and Moderate levels of need refer to a 'skin condition'. This is taken to mean a diagnosable condition such as skin cancer, psoriasis and cellulitis.

9. Breathing

- Fortunately the majority of people we have supported through their continuing healthcare assessments have not had significant problems with breathing, however a serious breathing condition can on its own result in eligibility for continuing healthcare if the person is assessed with a Priority level of need. The breathing domain has six levels of need ranging from No Needs to Priority, each with a descriptor to help you identify the correct level to apply.
- Has the person experienced any recent breathing difficulties such as shortness of breath or episodes of sustained breathlessness? Have they had any recent chest infections and if so, how long did each last and what treatment was prescribed to manage them? Does the person have a diagnosed breathing condition and is it responding to treatment?
- What treatment or equipment is in place to manage the breathing difficulty or condition? This may include the use of inhalers, nebulisers, oxygen therapy, ventilators, a tracheotomy or a form of mechanical ventilation. What are the doses and frequency, and how effective is the treatment?
- It is very important to describe in detail the way in which breathing conditions and their treatment impact upon the person's wellbeing as well as their ability to live a normal life. To what extent do breathing difficulties restrict the person's daily living activities? For some this may only impact on set periods of time during the day when the person must use a nebuliser. For others, their breathing condition may be so limiting that they are not even able to stand up without becoming breathless and therefore cannot walk, take part in activities, wash themselves or carry out personal care.
- Consider whether the breathing condition has an impact on other domains such as psychological and emotional needs. Is the breathing problem related to an anxiety disorder or exacerbated by a fear of not being able to breathe?

10. Drug Therapies and Medication: Symptom Control

- The medication domain has six levels of need ranging from No Needs to Priority, each with a descriptor to help you identify the correct level to apply. Many people will find it difficult to know how to engage in

a discussion with the multidisciplinary team about medication because they may not understand what the medication is for or the terminology involved in discussing its benefits. It is, however, important to try and understand how the person's condition and associated symptoms are managed through their medication regime, and the impact on their wellbeing.

- As a starting point, find out what medication the person is currently on and ask their care staff or GP what it is for. Is the medication regime considered to be complex or non-complex? Do any medications require a blood test for therapeutic levels? Is the medication regime stable or does it fluctuate, requiring close monitoring and adjustments?
- Is the person able to self-medicate or do they require prompts from carers? Is a registered nurse or a trained carer required to administer the medication on their behalf? Do any medications require supervision by a specialist such as a consultant or neurologist, for example? Are any medications administered 'PRN' (as needed) and if so is there a care plan in place for maintaining safe dosages and monitoring the effects of the PRN medications?
- Think about care staff's ability to administer medication. Is the person compliant with their medication regime or do they refuse it either physically or verbally? How many times per week do they refuse to take it? What measures are in place to ensure that medication is taken (such as retreat and return techniques)? If medication is missed due to a person's refusal to take it, what affect does that have on the management of the related condition and how does this impact on other domains? For example, if a person with challenging behaviour refuses to take prescribed antipsychotic medication, how would that impact upon the management of their behaviour (and associated risks of harm)? Is there a 'risk of relapse' if the medication is not taken?
- Pain management is an important factor to consider in the medication domain. From your knowledge of their physical needs, what level of pain does the person experience and how frequently? Would you classify the pain as mild, moderate or severe? Is the pain predictable (for example where it is triggered by a certain movement) or unpredictable? If you are unsure you can ask the care home or agency to complete a pain assessment chart. Is there a plan in place to manage the pain and control symptoms? Does the pain have an impact on the provision of care? If the pain symptoms are not controlled, have all treatment options and their associated risks been considered?

11. Altered States of Consciousness (ASC)

- The 'ASC' domain covers any condition which is significantly different from a normal waking state of the human brain, often manifesting itself as a temporary change in a person's mental state. ASCs should not be confused with the effect on the brain caused by dementia and other degenerative conditions. For that reason, cognitive impairment is discussed separately under the cognition domain.
- Typical episodes of ASC may be a CVA (stroke), seizure, Transient Ischaemic Attack (mini-stroke), or epilepsy, although there are multiple other examples. The ASC domain has five levels of need ranging from No Needs to Priority (but without a Severe level) each with a descriptor to help you identify the correct level to apply.
- Does the person have a history of ASC (for example strokes or seizures)? When was the last time the person experienced an episode? How long do the episodes tend to last? Did the person lose consciousness? Did they sustain any injuries during the episode? Was a carer required to supervise the person and reduce the risk of harm? What treatment or medication was put in place following the episode (if any) and did the person respond to that treatment? Are there any known triggers?
- Does the person have a diagnosis of a particular ASC condition and if so are they receiving any ongoing medication?
- Transient Ischaemic Attacks (TIAs) are often difficult to identify, particularly in people with cognitive impairment. Often a small TIA can manifest itself as a short 'vacant' period. This means that TIAs are not always recorded in care records which can make it difficult to assess the ASC domain accurately.

If you believe that the person is experiencing TIAs or other more subtle ASC ask the care home to look out for signs and keep a log in the weeks leading up to assessment.

12. Other Significant Care Needs to be Taken into Consideration

- This domain is designed to capture any significant conditions or occurrences that do not directly relate to one of the other domains. The type of occurrence that could be relevant to this domain are wide and varied but may include, for example, physiological conditions, haemorrhaging, excessive sleepiness, genetic conditions or even persistent nose bleeds.
- What is important is that you take time to stand back and think about the person and the totality of their needs. Is there any significant care need that has not been adequately addressed in the multidisciplinary assessment meeting? If so, discuss it and capture the detail in this domain. It has four levels of need ranging from Low to Severe, each with a descriptor to help you identify the correct level to apply.

The Key Indicators

The key indicators refer to the four key characteristics of need, which are *nature*, *intensity*, *complexity* and *unpredictability*. Once the multidisciplinary team (MDT) have assessed your needs and populated the Decision Support Tool they should consider whether any of these characteristics are sufficiently present in your care needs. The MDT should use the key indicators to decide whether the care you require is beyond the limit of the Local Authority to provide, in accordance with the Coughlan judgment. Each of the four key indicators may alone, or in combination, indicate a primary health need:

Nature

This refers to the characteristics of both the person's needs and the interventions required to meet them.

Things to think about when considering whether your needs sufficiently meet this key indicator:

- How do you and the multidisciplinary team involved in your care describe the need, rather than describing the diagnosed condition.
- What impact does the need have on your overall health and well-being?
- What care interventions are necessary to meet the need?
- Could anyone meet the need without specific training or is a particular knowledge or skill required?
- What would happen if your needs were not met at the right time? What would happen to you if care was not in place to meet your needs?

Intensity

This is about the quantity, severity and continuity of needs.

Things to think about when considering whether your needs sufficiently meet this key indicator:

- How severe is this need and what would happen if the need was not managed?
- How frequently is care intervention required to meet the need?
- How long does each care intervention take to manage or control the need?
- How many carers are required at any one time to meet the need?
- Does the management of the need affect multiple areas of care, across several domains?

Complexity

This refers the level of skill or knowledge needed to meet an individual need or a range of needs and the interplay between them.

Things to think about when considering whether your needs sufficiently meet this key indicator:

- How difficult is it for care staff to manage the needs?
- How difficult is it for care staff to alleviate the symptoms associated with the needs?
- Are the needs interrelated or dependent upon one another (for example the impact of incontinence and low weight on a person's skin condition)? How does this interrelation affect the management of individual needs?
- Is specialist knowledge, expertise or training required to meet the needs?
- Does the person's response to their condition or to care intervention make it more difficult to meet the needs (for example, refusal to take medication)?

Unpredictability

This concerns the degree to which a person's needs fluctuate and create challenges in managing them.

Things to think about when considering whether your needs sufficiently meet this key indicator:

- Are you or your care staff able to anticipate when the need might arise?
- How rapidly does the need change? Does the level of need change and how does the necessary care intervention have to adapt to meet the changing need?
- How much warning is normally given to alert care staff so that they can provide care intervention?
- Is the need or condition unstable?
- What would happen if the need wasn't managed when it arose? How significant would the consequences be?
- Is specialist knowledge, expertise or training required to respond to the need spontaneously and appropriately?
- What level of monitoring is required?

Care Planning

Once you are assessed as eligible for continuing healthcare the NHS become responsible for the management of your care. It is their responsibility to ensure that the care provision meets your assessed health and social care needs, whether they be psychological, emotional, physical or mental health needs.

The Clinical Commissioning Group (CCG) should consult with you regarding your preferences and commission care services which maximise personalisation and offer individual control. If your preferred care arrangement is more expensive than the CCG wants to commission and if they can demonstrate that your needs could be met in a less expensive care setting, they do have the right to commission the less expensive care service.

The CCG have a responsibility to take into account your preferences and to ensure that moving you to a new care setting or selecting a different care agency will not have a detrimental effect on your health. The CCG should also demonstrate that they have investigated all available options (such as negotiating a reduced rate with the care home or care agency) for keeping you in your current environment before deciding to change your care.

Part of the continuing healthcare assessment process involves ensuring that your current care arrangement is suitable and meeting your assessed needs. If either you or your CCG are unhappy with the quality of care being delivered in your current setting, then it may be possible for you to move somewhere more appropriate as long as the CCG deem the alternative care setting suitable to meet your assessed needs.

If your care was managed by social and community services before you became eligible for continuing healthcare, the CCG should not make changes to your care setting just because responsibility has shifted from the Local Authority to the NHS, due to the potential disruption to the management of your care.

Topping-Up your Care

Because continuing healthcare is based upon your assessed needs and not your ability to pay, the CCG cannot set arbitrary caps on funding, nor can they ask you to 'top up' your own care. To do so would be unlawful because it breaks one of the founding principles of the NHS. The only situation in which top-ups would be permissible is if you chose to pay for extra support that is not intended to meet your assessed health and social care needs, and which could be clearly separated from your current care provision.

CCGs cannot impose a charge on you or your family because they feel that your care home is more expensive than they would like to pay, even if they believe that it provides you with non-essential services, because those services could not be clearly separated from the rest of the care you receive in your care home.

Personal Health Budgets

As of April 2014 every person who is eligible for continuing healthcare should be offered a personal health budget. The aim of giving people (or their representatives) their own budgets to manage is to promote genuine choice and control over how your assessed care needs are met by providing you with the flexibility to choose your own care provision, within certain boundaries.

If you decide that you would like a personal health budget your Clinical Commissioning Group (CCG) should work with you to set personalised care and wellbeing goals, based upon the assessed needs detailed in your care plan. The CCG will offer you an indicative budget based upon these goals. CCGs may also offer free and independent brokerage services to help you create a support plan and to find appropriate services.

Personal health budgets can be managed in different ways. For example, you may decide that you wish to receive the cash so that you can buy in and manage the care and support services that have been agreed upon in your support plan. However, you do not actually have to handle the money or manage the care yourself, if you don't want that responsibility. Opting for a 'notional budget' gives you choice and control whilst leaving the complexity of employing and managing care services to the NHS.

Between 2009 and 2012 the Department of Health ran a pilot programme for personal health budgets with Oxfordshire chosen to be one of the in-depth pilot sites. Our team at Beacon were heavily involved in the pilot through Age UK Oxfordshire from the outset, which gave us the opportunity to influence key strategic decisions from an independent perspective on behalf of our clients.

For more information we recommend that you visit NHS England's dedicated website for personal health budgets at; www.personalhealthbudgets.england.nhs.uk.

The Closedown Process and Retrospective Assessments of Continuing Healthcare

In July 2007 the Department of Health announced a cut-off date of November 2007 for individuals who wished to request a retrospective review of a period prior to April 2004. This was in response to the high number of cases still in the system since the retrospective review process was initiated in 2003.

In March 2012 the Department of Health announced new timescales for challenges to assessment decisions and cut-off dates for individuals wanting to request an assessment for a previously unassessed period of care, in an attempt to end ongoing requests for retrospective reviews completely. This was the first time timescales had been imposed for challenges to assessments. The announcements meant that:

- If you received long term care between April 2004 and April 2011 but had never been assessed for continuing healthcare you had until 30th September 2012 to request a retrospective review.
- If you had been assessed for continuing healthcare between April 2004 and March 2011 but not awarded funding, you had until 30th September 2012 to appeal that decision.
- If you had been assessed for continuing healthcare between April 2011 and March 2012 but not awarded funding, you had until 31st March 2013 to appeal that decision.

As a result of the Department of Health's announcement and the media awareness campaign that followed, Primary Care Trusts were inundated with an estimated 60,000 requests for retrospective

reviews. Many PCTs were completely unprepared for this deluge with neither the administrative staff nor the assessment coordinators to begin processing this number of requests, let alone the estimated £600million figure needed to pay restitution for cases where the person in question was assessed as eligible. This has led to significant delays and backlogs with thousands of applicants meeting a wall of silence when trying to follow up the progress of their review request.

Beacon's team have recently been involved in providing training to Clinical Commissioning Groups on how to interpret the assessments toolkits that were in use in the Thames Valley prior to the introduction of the National Framework to ensure that individuals who have applied for a retrospective review are not penalised by a lack of understanding of contemporaneous assessment processes.

We are disappointed that the NHS Commissioning Board has introduced lengthy and complex request forms for people who wish to request a retrospective review of a previously unassessed period of care, and instructed them to access their own care records. These forms ask applicants to specify whether their needs were intense, complex or unpredictable and to explain why they believe they have a primary health need as oppose to a social care need.

In what context are these questions being asked? Unless people who require a review have the many hours required to study the hundreds of pages of National Framework and supporting documentation in order to understand the complexities of the primary health need test and key indicators, the majority will not be in a position to accurately complete the request forms, which in turn will lead to many being refused a review simply because they are not continuing healthcare experts.

There are also questions over what constitutes a 'previously unassessed period of care'. The application forms ask you to list the assessments that have previously been carried out. This is to establish whether the period in question was assessed either as a full consideration or as part of the continuing healthcare screening process that was in place at the time. In order for the NHS to reject a request for review on the grounds that the person already received a continuing care assessment at the time, there must be written contemporaneous evidence that clearly shows continuing healthcare was considered alongside evidence for each care domain.

A sentence on a decision letter written at the time stating that the person was not eligible for continuing healthcare is not enough on its own to demonstrate a robust screening assessment process had taken place. Unfortunately, many people assessed prior to the introduction of the National Framework in 2007 were completely unaware that any kind of continuing healthcare assessment had taken place because they were not asked to be involved and did not receive a decision letter. Asking them to list previous assessments on a review application form is unfair, to say the least.

We recommend that people wishing to complete an application for a review of a previously unassessed period of time use the information contained in the sections Making Sense of the Domains, and The *Key Indicators*, above, to help them understand the terminology and complete the forms with relevant information. If you are unsure as to whether the period of time you wish to have assessed has ever been assessed in the past;

1. Write to your Clinical Commissioning Group asking them to provide you with copies of any previous assessments (including any RNCC or FNC assessments) and then;
2. Look through the previous assessments for evidence that continuing healthcare eligibility was properly considered, either in a screening process or full assessment process. If this is not evidenced then you are within your rights to insist upon a retrospective screening Checklist of that period.

References

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Department of Health, Fast Track Pathway Tool for NHS Continuing Healthcare November 2012 (*Revised*)

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Further Contact

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