Beacon
leading you through the maze of continuing healthcare

Beacon Navigational Toolkit

– Guide to Continuing Healthcare Appeals

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Introducing the Navigational Toolkit

This free appeals 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', below.

How to Use This Guide

This guide is aimed at:

- people who have received a Checklist assessment which concludes that you are not eligible for a full continuing healthcare assessment, and you wish to challenge the decision;

or

- people who have been assessed through the full assessment process and received a decision that you are not eligible for NHS continuing healthcare, and you wish to appeal the decision;

or

- people who are already in the appeal process and need further information and advice.

If you have not yet been assessed for NHS continuing healthcare we recommend that you start by reading our *Guide to Continuing Healthcare Assessments.*

Some of the information and guidance we refer to in this guide can be found in our *Guide to Continuing Healthcare Assessments.* If you do not have a copy we recommend that you download it from our website so that you are able to refer to the relevant sections mentioned in this guide.

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.

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 it 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.

A Few Things to Bear in Mind

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.

How to Appeal a Checklist (screening) Decision

Grounds for Appealing a Checklist Decision

Checklist decisions cannot strictly be appealed, although you do have the right to request a *reconsideration* of a decision and then access the *NHS complaint procedure* if you remain dissatisfied.

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' in our *Guide to Continuing Healthcare Assessments*) 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

If you meet any of this criteria, 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.

Furthermore, you do not necessarily have to meet this criteria in order to be offered a full assessment, so if you have not met the criteria above but you still feel that you may have a primary health need, you can ask the CCG to reconsider its decision.

We recommend that you carefully read the Checklist document to check whether your understanding of your health and social care needs fits with the descriptor that has been assigned in each of the 11 care domains. If you feel that the Checklist is inaccurate, write down the specific reasons as to why you feel a particular domain or area of need is inaccurate. For example, if you are doubly-incontinent you would usually be assessed as meeting the 'B' descriptor in the continence domain. If the Checklist specifies that you meet the 'C' descriptor, the Checklist may well be inaccurate and you should ask for it to be reconsidered.

Checklists are often completed by hospital, care home or community health professionals rather than coordinating assessors. 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.

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 or feel that they have misapplied the evidence from your care records, you can ask the CCG to reconsider its decision.

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.

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.

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. If this has not happened, you have grounds for complaint.

The Review and Complaint Process

If you have received a Checklist assessment – which is the first stage of the assessment process – and you do not fulfil the criteria for a full assessment, you can ask the Clinical Commissioning Group (CCG) to reconsider its decision. Following completion of the Checklist you should have received a decision letter which explains why you are not eligible for a full assessment and your rights to challenge that decision. If not, you should contact the professional who completed the Checklist or your CCG. You can find contact details for your CCG by searching for 'services near you' at www.nhs.uk.

If the decision remains the same after the CCG has reconsidered it, you have the right to access the NHS complaint procedure. This is a 2-stage process which consists of:

A. Sending a written complaint to the CCG complaint manager setting out the reasons why you feel you are entitled to a full assessment and why you disagree with the Checklist outcome. It is a good idea to specify which areas of need (domains) you disagree with and provide any evidence that will

support your views, such as care plans, GP records or hospital records. Complaints must be properly investigated and you should receive a full written reply.

B. If you still remain dissatisfied with the CCG's response you can refer your complaint to the Parliamentary and Health Service Ombudsman by visiting www.ombudsman.org.uk or phoning 0345 0154033.

How to Appeal a Full Assessment Decision

Timescales for Appeal

When your continuing healthcare assessment has been completed you should receive a decision letter informing you of the outcome and explaining how the eligibility decision was reached. You have 6 months from the date of that notification to request a review of the decision. The Clinical Commissioning Group (CCG) then have 3 months from the date of your request in which to review the decision and complete the local review stage.

Following completion of the local review stage you then have 6 months from the day you are notified of the CCG's decision to request an Independent Review Panel (IRP). The NHS Commissioning Board must convene an IRP within 3 months of your request.

If either the CCG or the NHS Commissioning Board take longer than 3 months to complete the local review stage or to convene an IRP, you have grounds to complain through the NHS complaint procedure (above).

Grounds for Appealing a Full Assessment

If you have received a full continuing healthcare assessment and disagree with the outcome, you have the right to appeal. You can appeal if you disagree with the *eligibility decision* or the *procedures* used by the CCG to come to that decision. You cannot appeal against the continuing healthcare *criteria* itself, since CCGs have no influence over the criteria that they must use, but you can appeal if you disagree with how the criteria have been *applied*.

You should have received a decision letter from your Clinical Commissioning Group (CCG) containing a rationale for how the decision was made which should help you to prepare for your appeal. The letter should also explain how to contact the CCG if you wish to appeal.

When you receive this letter, we recommend that you 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.

Starting the Appeal Process

To request a review of the CCG's decision and begin the appeal process you will need to write to the CCG outlining your reasons for requesting a review. Having first read through the CCG decision letter to understand why they have assessed you as ineligible, and considered the procedural grounds checklist, above, we recommend that you refer to the following areas when preparing your letter:

A. Was the assessment procedure correct?

- Did the CCG fully involve you and/or your representative in the assessment process, giving you ample opportunity to contribute your views?
- Were all the health and social care professionals recently involved in the delivery of your care invited to take part in the assessment?
- Was the multidisciplinary team appropriately constructed? (see 'More About the Multidisciplinary Team' in our Guide to Continuing Healthcare Assessments)
- Were all members of the multidisciplinary team involved in making a recommendation regarding eligibility?
- Was the assessment process concluded within 28 days of the date of referral?
- Are there any other procedural failings from the checklist above you wish to highlight?

B. Do you disagree with the assessment or any of the levels of need applied in the Decision Support Tool?

- Did the information provided in each section of the Decision Support Tool (care domains) accurately represent your needs and how those needs are met?
- Is there further written evidence such as care records which have not previously been considered that could make a difference to the assessment or eligibility decision?

- Did the Decision Support Tool contain references to evidence (such as care records) that you believe to be incomplete or inaccurate and which paint a distorted picture of your overall needs?

C. Do you disagree with the conclusions reached?

- Did the multidisciplinary team make a *firm recommendation* regarding eligibility following a *meaningful discussion* about your overall needs?
- Did the CCG uphold the recommendation of the multidisciplinary team or if they did not, were any exceptional circumstances presented?
- In coming to a decision regarding eligibility did the CCG consider your needs against the key indicators of nature, intensity, complexity and unpredictability? (see 'The Key Indicators' in our *Guide to Continuing Healthcare Assessments*)
- Did the CCG's decision letter provide a *clear rationale* for how the eligibility decision was reached?
- Explain as clearly as you can why you disagree with the conclusions of the CCG and why you feel that you have a *primary health need*. If you can, make reference to the key indicators of intensity, complexity and unpredictability. Use specific examples from your knowledge of how your care needs are met.

Stages of Appeal

The appeal process usually consists of three stages:

A. The first stage of appeal is through the CCG's local review process which may vary depending on where you live, but often involves a resolution meeting with the CCG continuing healthcare team. During the review process the CCG should try to resolve the matter informally without the need for further appeal stages.

   At Beacon we find that as long as resolution meetings are handled well by the CCG they can be a valuable opportunity for you or your representative to ask questions about the assessment and to gain a better understanding of why the CCG has come to its conclusion regarding eligibility. The CCG may also decide to convene a fresh local panel to reconsider the eligibility decision if they believe there is evidence available which has not previously been considered or the original decision may be unsound.

B. The second stage of appeal is to refer your case to the NHS Commissioning Board for an Independent Review Panel (IRP). Your local CCG should provide you with information about how to refer your case for an IRP at the end of the local review stage.

   An IRP provides a formal review of the CCG's decision and the procedure it followed using a panel of experienced health and social care professionals who are independent of the CCG which carried out the assessment. You will be invited to attend part of the panel hearing to present your reasons for appealing and to answer any questions the panel may have about your specific needs. The IRP will make a recommendation to the CCG which should be accepted in all but exceptional circumstances.

C. The third stage is to refer your case to the Parliamentary and Health Service Ombudsman for review and possibly a full independent investigation. Depending on this outcome there may be further local appeal stages involved.

   The first two stages should not normally take longer than 12 months to complete however it is not uncommon for cases to last several years and require multiple panels before all available appeal options have been exhausted.

How to Prepare for the Local Review Stage

If you have not done so already, we would recommend that you come to any resolution meeting prepared to talk about your reasons for disagreeing with the eligibility decision or the process of

assessment. You can prepare your reasons by thinking about the areas outlined in the section 'Starting the Appeal Process', above.

We recognise that families and friends of people who are going through the continuing healthcare system are often doing so at an emotionally difficult time and that the system itself can be mentally and emotionally exhausting. Nevertheless, we strongly recommend that whoever attends the meeting comes prepared to talk specifically about how the needs of the person relate to the care domain *levels of need* in the Decision Support Tool, the *assessment procedures* used by the CCG and the overall *eligibility decision*. You may find it useful to make a note of the most important items you want to discuss with the CCG in advance.

To gain a better understanding of how to interpret the care domain levels of need, please read the section 'Making Sense of the Domains' in our *Guide to Continuing Healthcare Assessments.*

There is often a gap of a few weeks between your request for a review of the decision, and the start of the local review stage. If you are uncertain about whether the Decision Support Tool (DST) provided a completely accurate portrayal of your needs you may find it useful to ask a friend or relative to keep a detailed diary of how you presented during their visits and compare this to the DST. Be aware though that needs can change over time and you may not present with exactly the same needs as you did at the time of assessment.

We recognise that often people feel intimidated when discussing continuing healthcare with professionals who work with the criteria every day, because it is such a complex area of health policy. People can sometimes feel 'baffled by science'. Try not to let that stop you asking questions and insist that the CCG clearly explain their reasons for coming to the conclusion that you are not eligible.

Winning Your Appeal at the Local Review Stage

Although many CCGs hold resolution meetings as part of their local review process, the term 'resolution' is perhaps a little misleading. In our experience this stage of appeal rarely leads to resolution. This is because CCGs are often unwilling to overturn a decision that is based on a detailed assessment without it being fully re-considered by a multidisciplinary team or panel. Likewise, the person who has asked for a review is unlikely to accept the eligibility decision without it being formally reconsidered. Instead, resolution meetings tend to be a good opportunity for people to find out more information about how the decision was reached and to raise any concerns they may have about, for example, the assessment procedure or the evidence used.

As long as resolution meetings are carried out in an inclusive and informative way our clients generally find them to be a useful first stage in the appeal process. However, more often than not people will proceed to further stages of appeal. It is advisable to ask the CCG to provide you with written minutes of any meetings or panels that take place during the local review process.

If the CCG decides to convene another 'local' panel to consider your case again (for example if new evidence has come to light), it is possible that the panel will find in your favour without you having to take your appeal any further. You can ask to attend this panel and we recommend that you do so, although it is at the CCG's discretion as to whether or not they allow you to attend.

Remember that no matter how insistent the CCG may be that there is little chance of success if you take your appeal further, you have the right to ask for your case to be formally reviewed by an Independent Review Panel (IRP) for a second opinion. Try not to be pressured into giving the CCG a decision on the spot as to whether or not you intend to take your appeal further, you have 6 months to decide whether to request an IRP following completion of the local review stage.

How to Request an Independent Review Panel (IRP)

Once the local review stage has been completed, the CCG should provide you with information about how to refer your case for an IRP. This is done through your regional continuing healthcare department of the

NHS Commissioning Board (The Board). You should write a short letter to The Board requesting an IRP to review a continuing healthcare decision, explaining that you have completed the local review process and briefly outlining your reasons for appeal.

The Board will send you a formal IRP request form to complete. The form will ask you to explain your reasons for requesting an IRP in more details, and will encourage you to specify any complaints you have about the process of assessment, as well as your views regarding the eligibility decision. We recommend that you use the reasons set out in your letter to the CCG in which you outline the reasons for requesting a review, as a starting point. This should capture grounds relating to the process of assessment and the eligibility decision. You should also explain that the local review process has been completed and make reference to any matters that arose from the local review process you wish to make the IRP aware of.

This form should be returned to the NHS Commissioning Board along with any paperwork relating to your authority to act on behalf of the person for whom you have a requested an IRP. 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) you will need to provide evidence to The Board that the person has appointed you to act as Lasting Power of Attorney on welfare matters, or that you have been appointed personal welfare deputy by the Court of Protection. If the person is no longer alive you will need to demonstrate that you are Executor of the Estate.

How to Prepare for an Independent Review Panel (IRP)

Write down everything you want to tell the IRP about your reasons for requesting an IRP.

If you have not done so already we recommend that you come to the Independent Review Panel (IRP) prepared to talk about any failings in the assessment procedure you have identified, and your reasons for disagreeing with the *eligibility decision*. We recommend that you consider whether you have any grounds to challenge how the assessment was carried out by working through the procedural grounds checklist in the section 'Grounds for Appealing a Full Assessment', above.

We also recommend that you spend some time working through each of the care domains in your Decision Support Tool alongside the section 'Making Sense of the Domains' in our *Guide to Continuing Healthcare Assessments.* From your knowledge of your health and social care needs, do you agree with the levels of need that have been applied in each domain? If not, are there any care records or specific memories of past events that support your view?

For example, the Decision Support Tool may conclude that you only experience *mild pain* on an *occasional* basis, particularly if you do not often complaint about being in pain to the care staff. However, if in reality you experience a *significant* amount of pain on every care intervention, it is important that you bring this up at the IRP. You should try to use knowledge of your care needs together with the written care records, the views of your family and friends, and any visitors diaries that have been kept to challenge any area of the Decisions Support Tool that you feel is inaccurate.

Finally, try to write down your thoughts about how your needs meet the key indicators of nature, intensity, complexity and unpredictability, using the section 'The Key Indicators' in our *Guide to Continuing Healthcare Assessments to help you.*

Writing down your thoughts into a statement will help you to stay focussed during the IRP and ensure that you don't forget to mention anything important. As long as what you have written doesn't contain new evidence, it may be helpful for you to bring copies of it with you to the IRP for panel members to refer back to during their deliberations.

Send The Board everything you think may be relevant.

The NHS Commissioning Board will gather all of evidence relating to your care needs that is relevant to the period of assessment. Typically, an evidence pack may contain GP records, care home or care agency records, care plans, risk assessments, daily reports, hospital records and Local Authority records amongst others.

The evidence pack should also contain information that you want to be considered. This might be a private diary that you or someone else has kept about your care needs, a statement detailing your reasons for disagreeing with the eligibility decision, an independent care assessment you have commissioned or anything else you feel is relevant. This is the only evidence that will be considered by the IRP when reviewing your case so it is important that you submit anything you feel is important to the Commissioning Board well before the panel date.

Make sure the IRP is reviewing the right time period and stick to it.

For a 'current' case (one that is not for a retrospective time period) the relevant time period will usually be the date on which the multidisciplinary assessment took place, so it is good practice for the evidence compiled by the NHS Commissioning Board to relate to this period and the months immediately preceding it. You should try to base your arguments and views on the same time period. For example, you may have presented with aggressive behaviour whilst you were living at home but that behaviour became more manageable since you went into a care home.

If the continuing healthcare assessment was carried out 3 months after you went into the care home then try to focus your argument on the care needs you presented with since you went into the care home because the previous aggressive behaviour will no longer be directly relevant to this assessment.

Read the evidence file thoroughly

A copy of the evidence that will be considered by the IRP members should be sent to you and all the panel members in advance of the panel. This contains all the evidence that the IRP will use to help them make a decision. You may find entries in care records that you disagree with or which contradicts the information you have provided in your submissions to the IRP. It is a good idea to know what is in the evidence file so that you can answer any questions IRP members have or make them aware of any inaccuracies.

What to do During the Independent Review Panel

What to expect and who to expect

IRPs are formal review panels with specific terms of reference but they should be run in a way that is welcoming, free from intimidation and not *overly* formal. Panel members need to understand as much as possible about your care needs in order to come to a fair decision, so it is in their interest to try and put you at ease so that you feel able to share.

The IRP panel members must be independent of the CCG which was responsible for assessing you for continuing healthcare. The panel will be made up of health and social care professionals in decision making roles and also specialist clinical advisers in non-decision making roles. These professionals may well be employed by the NHS or a Local Authority in a different area so they will not necessarily be independent of the NHS, but they must be independent of your CCG.

Because continuing healthcare assessments are multidisciplinary, IRPs which are convened to review eligibility decisions must also be multidisciplinary.

The panel will be chaired by a Chair Person who is currently independent of the NHS and with experience of chairing panels. This ensures that IRPs have an influential member on the panel who is fully independent of the NHS. The Chair can also act in a decision making capacity and could provide a casting vote although they are encouraged to find consensus wherever possible. It is the role of the Chair to facilitate panel proceedings and to chair the panel meeting in an impartial manner, ensuring that both the person to whom the IRP concerns and the CCG representative are treated fairly and given equal opportunity to share their views, and to contribute to the IRP.

There may be other people present during the IRP, such as an administrator, a facilitator working for the NHS Commissioning Board, or an observer. Try not to be intimidated by the number of people in the room and direct your comments to the decision-makers or to the Chair Person.

Your involvement in the IRP

The NHS Commissioning Board should invite you or your representative to attend the panel and to submit any supporting information you wish to include in the evidence pack. The Board should also provide you with an agenda so that you can see how the panel will be run and which parts you will be invited to contribute to.

The Board will also invite a representative of the CCG to attend the IRP so that they can explain to the panel how they came to their conclusions as to the correct levels of need to apply in each domain, how they arrived at their eligibility decision, and also to answer any questions that panel members may have. Be assured that the CCG representative is not a decision-maker and must enter and leave the room at the same time as you, so that the IRP is seen to be fair and transparent.

How does it work?

When you arrive, the Chair Person will often meet you just before the panel hearing begins to introduce themselves and run through the agenda. This is your opportunity to ask any last-minute questions you may have about the IRP. The Chair should explain how and when they will ask you to talk about your views.

It is normal for people to be given time at the beginning of the IRP to explain why they disagree with the CCG's eligibility decision, to present their views about the person's care needs and the levels of need in the Decisions Support Tool, and to highlight any concerns that you may have about the CCG's assessment procedures.

You will be given a set amount of time in which to contribute your views and answer any questions the panel may have so we recommend that you refer to the points and arguments you prepared in your statement, and try to stay on track so that you will leave the IRP satisfied that you have said everything that you feel is important.

Panel members may wish to ask you questions about your care needs or about any points you have raised. Remember that their role is to understand your needs in as much details as possible so that they can apply the criteria accurately, so don't be afraid to answer their questions in detail, but try to answer them directly.

Helping the panel to understand the 'person'

IRP members are independent of the CCG which completed the assessment and will have had no prior involvement in your case, so the only information they have to help them understand your care needs as an individual are the care records they read in the evidence pack. You or your representative can play a significant role in helping IRP members to understand the 'person'.

It is a good idea to provide the panel with some background information about your history and personality before you developed your care needs. This will help provide a context which can result in a more accurate review.

For example, if you have dementia and present with anxiety and tearfulness in a care environment, withdrawing yourself from social interaction; it may be useful for the panel to know whether you were a nervous or confident person before you became ill so that they can assess whether or not your behaviour is out of character. This would not necessarily change the need (anxiety), but it would help them to understand how your physiological needs interact with other factors such as cognitive impairment caused by the dementia.

Understanding the panel's remit

When you request an IRP you are asking the NHS Commissioning Board to convene a panel of health and social care professionals whose job it is to understand your needs in detail and apply the continuing healthcare criteria to those needs as accurately as possible.

The panel are not legal experts so there is little point in constructing a complex legal argument in the hope that it will persuade them to recommend that the NHS pay for your care. Likewise, the panel cannot consider whether or not the National Framework and criteria are fair or legal, their job is simply to apply the framework and criteria which is currently in use.

We understand that the continuing healthcare assessment and appeal processes are lengthy, complex and frustrating, and that all this is often occurring at an emotionally difficult time for you and your family. We also understand from experience that procedural failures along the way can make the entire system seem thoroughly unfair and feel like you are a lone voice fighting the NHS to get justice.

It's ok to show some emotion in the IRP and it is very important to tell panel members about all the frustrations and procedural failures you may have encountered, so that the responsible Clinical Commissioning Group can be held to account and helped to improve. However it is also important to remember that the IRP members themselves are new to your case. They cannot change the criteria and have no financial pressures because they are independent of the CCG which carried out your assessment. They should be here to work *with* you and not against you.

The best thing you can do to give your appeal the greatest chance of success is to help the panel members to understand in as much detail as possible about your day-to-day *care needs* and *how those needs are met.* Talking about the failures of the NHS or explaining that you have paid your taxes all your life and are owed some support from the state are all important arguments, but ultimately the eligibility decision will come down to care needs alone. The *only* way you will win your appeal is if those panel members conclude that your care needs were of a nature, intensity, complexity or level of unpredictability to make them primarily health needs.

For this reason it is crucially important to focus your arguments on your needs as they were at the time of assessment.

What Happens After the Independent Review Panel

You should receive a full report from the IRP containing the recommendation they have made to the NHS Commissioning Board and to the Clinical Commissioning Group regarding your eligibility for continuing healthcare, with a comprehensive summary of the IRP's deliberations. The report should identify the levels of need that the IRP have chosen to apply in each of the 12 care domains as well as enabling you to understand the rationale for their decisions. It should also contain a detailed explanation as to how your care needs meet the key indicators of nature, intensity, complexity and unpredictability. Finally, the report should make reference to any procedural failings you raised at the IRP, and recommendations as to how these should be addressed.

The IRP's recommendations should be accepted by both The Board and the CCG in all but exceptional circumstances.

If your appeal is successful, the CCG should write to you explaining how responsibility for managing your care will be transferred to the NHS. If you are due any financial restitution, you should receive a letter requesting that you submit copies of documents to justify what you have spent on care fees. These can be, for example, invoices from the care provider or copies of bank statements. If your case relates to a retrospective assessment of a previously unassessed period of time, you may also be due interest. In either case, you should ask for a full financial calculation so that you can see how the sum has been arrived at.

How to Request an Ombudsman Investigation

If you remain dissatisfied with the IRP's eligibility decision, you may now refer your case to the Parliamentary and Health Service Ombudsman for a review and possibly a full independent investigation (depending on the outcome of the review). The PHS Ombudsman can consider procedural failings and

the application of the criteria. Strictly, the PHS Ombudsman's role is to consider whether or not the IRP was carried out according to due process, however even if the IRP was carried out correctly, if you do not feel that it adequately dealt with procedural failings earlier on in the assessment process, you can ask the PHS Ombudsman to look into the way in which the IRP has responded to those failings.

There are no specific time scales for completion of a PHS Ombudsman review or investigation other than their own internal targets, so it may take a number of months for your case to be resolved. It is also possible that the PHS Ombudsman will choose to refer your case back to The Board or to the CCG for another panel hearing, or a re-assessment, which may significantly extend the length of your appeal. It is important to be aware that, contrary to what many people think, the PHS Ombudsman is not able to instruct The Board or the CCG to overturn its decision and find you eligible. It can, however, make strong recommendations.

To refer your complaint to the Parliamentary and Health Service Ombudsman by visiting www.ombudsman.org.uk or phoning 0345 0154033.

Finding Somebody Independent to Guide you Through the Appeal Process

Be Wary of Anybody who Tells you they can Definitely Win Your Case

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. Unless the person who has 'promised you success' has been through this comprehensive assessment process with you, it is very unlikely that they would be in a position to know whether you are eligible just by filling out a form or having a brief chat with them.

Furthermore, eligibility cannot be guaranteed unless the person is certain that you had either two Severe levels of need or a Priority level of need across the care domains in the Decision Support Tool, and had the evidence to demonstrate this combination of needs. In our experience relatively few individuals are assessed with this combination of needs.

If you have received assurances from anyone that they can 'guarantee' your 'claim' for continuing healthcare we would advise you to carefully check exactly what grounds they base their conclusions on and be certain that they have *considerable* experience in dealing with continuing healthcare cases before going any further.

Paying for Representation

Appealing a continuing healthcare assessment is challenging and time-consuming, but it 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 challenge a wrong eligibility decision or poor assessment procedure on your own. We hope that our free Navigational Toolkit will enable many more people to do just this.

It is important to note that the NHS Commissioning Board has a scrutiny and reviewing role in the appeal process, they use health and social care professionals rather than legal professionals to do this on their behalf. The appeal process is not a legal process and legal submissions will not be heard by review panels. At each stage of the assessment and appeal process, the people making decisions regarding your eligibility for 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 advisable to focus an appeal on the intricacies of case law when the remit of the panel is to understand your personal needs and apply health criteria to them. For this reason it is not necessary to use a solicitor to appeal your assessment, in fact the guidance recommends against

having legal representation at appeal panels. There is a place for the legal process, but this generally comes after the appeal process has been exhausted.

Due to the highly specialised nature of NHS continuing healthcare it is important that you find an organisation with the right expertise and considerable experience in the field to support you.

If you feel that you need to pay for specialist advocacy to manage your appeal, we strongly recommend that you find out the following information before instructing a firm so that you are able to make an informed choice:

A. How long have they been specialising in the field of NHS continuing healthcare?

B. How many cases have the worked on?

C. How many cases have they won at appeal?

D. Have they worked on a broad range of cases or just those which affected their own family/friends? Do they have a breadth of experience?

E. What is their charging model and how much do they charge per hour/case?

F. How long will it take for them to resolve your case – what is the likely final cost?

G. If they offer a 'no win no fee' service can they guarantee that they will not introduce surprise upfront costs at any time? Get this in writing.

H. If they offer a 'no win no fee' service what percentage of restitution will they take following a successful outcome, including VAT and interest?

I. If they offer a 'no win no fee' service and agree to take on your case, do they guarantee not to drop you if the case becomes too difficult or it looks like you may not win?

J. Can they explain to you how they will go about resolving your case?

K. Are they proposing to take your case through the appeal process or through a legal challenge, or both? (Remember that the appeals route should be completed first and is completely free should you wish to go it alone).

References

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

Parliamentary and Health Service Ombudsman, Retrospective continuing care funding and redress, 3rd Report, Session 2006-2007

working in partnership with

Further Contact

For further independent information, advice and advocacy regarding NHS continuing healthcare, contact Beacon at:

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Tel: 0345 548 0300 **www.beaconchc.co.uk**

Beacon
leading you through the maze of continuing healthcare

The information provided in this guide is applicable in England but different rules and processes may apply in Wales, Northern Ireland and Scotland.

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