



Beacon Navigational Toolkit

– Continuing Healthcare Legal Background

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Introducing the Navigational Toolkit

This free legal background 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*.

Significant Cases and their Relevance to NHS Continuing Healthcare

Leeds Ombudsman Case, 1994

The patient involved was a man with severe brain damage who was discharged into the community by Leeds General Infirmary with no follow-up care or funding in place. Although his needs had stabilised, he still required a significant amount of nursing care for the rest of his life and so his wife paid for his care in a private nursing home.

The Ombudsman upheld the complaint on the grounds that Leeds Health Authority had failed to appreciate that a need for substantial nursing was itself sufficient to entitle a patient to NHS continuing healthcare and that it was unreasonable for the authority to implement a policy that failed to make long-term NHS care available.

Coughlan Case, 1999

In July 1999 the most important (and well known) legal case concerning NHS continuing healthcare was concluded, that of Pamela Coughlan. Coughlan was injured in a road traffic accident in 1971 and as a result is now tetraplegic and wheelchair dependent. Pamela Coughlan is paralysed in the lower part of the body and has no movement in her legs with only limited movement in the upper part of her body. She suffers with serious physical impairment and a number of neurological conditions.

In 1972 Coughlan was transferred to Newcourt Hospital in Exeter where she remained for 21 years. In the late 1980s rumours surfaced that the health authority planned to close the hospital since it could not be suitably refurbished. Following a residents' campaign against the closure, a compromise was suggested whereby if residents agreed to move into a purpose built unit at Mardon House, it would be their 'home for life'.

Despite this assurance, in 1997 residents were informed that Mardon House was to be sold because the NHS did not consider any of the residents to be their responsibility, effectively deciding that the residents were not entitled to NHS continuing healthcare. Coughlan and her lawyer challenged the decision and the High Court found in her favour in 1998. The health authority and Department of Health appealed the decision but this was dismissed by the Court of Appeal in 1999.

The Coughlan judgment is without question the most important benchmark case in NHS continuing healthcare, and one that is often misunderstood. The judge in the case of Coughlan ruled that not only were her needs primarily health needs that could not lawfully be provided by the local authority, but that Coughlan herself required services of a *wholly different category*.

The eligibility criteria for continuing healthcare applied in the case of Coughlan were judged to be far too restrictive and this judgement resulted in every health authority being instructed to review its local criteria

to ensure that it was 'Coughlan compliant'. Essentially this meant that local authorities could only legally provide healthcare services that were:

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

Ultimately the Coughlan case highlighted that if an individual has healthcare needs that are over and above that which social services can be expected to provide and are therefore primarily health needs, the NHS has a responsibility to provide for those needs, and to fund the necessary care.

Pointon Ombudsman Case, 2003

Mr Pointon suffered from Alzheimer's disease and had a range of mental and physical health care needs. These included incontinence, cognitive impairment, verbal communication difficulties, inability to feed himself and a requirement for constant supervision and reassurance.

The Ombudsman found that Department of Health guidance had not been properly followed because the continuing healthcare assessment tools used in his case were too focussed on physical needs to the detriment of his psychological needs. Furthermore, Mrs Pointon was providing a high level of personalised care with great skill. The fundamental principle established in this case was that the nursing care provided by Mr Pointon's wife was equal to, if not superior to that which Mr Pointon would have received in a hospital dementia ward.

This challenged the assumption that nursing care can only be provided by qualified nurses. The ruling led to the principle that NHS continuing healthcare could be provided in any setting, not just care homes with nursing. Furthermore it led to a cultural understanding that assessment toolkits should be needs focussed rather than dependent upon whether or not the need is being met by a specialist.

Grogan Case, 2006

In the case of Grogan vs Bexley Primary Care Trust the High Court ruled that eligibility criteria used by the Primary Care Trust were unlawful because it contained no guidance regarding the primary health need approach which defined the limits of a local authority's responsibility to provide healthcare. This meant that there was the possibility of confusion around what test should be applied by the decision-makers when deciding upon the eligibility of an individual. The judgment also found the Department of Health's guidance on the primary health need approach to lack clarity.

The judgement also gave way to the term dubbed 'Grogan gap' in which it is possible for individuals to fall between health and social care provision. Strategic Health Authorities and Primary Care Trusts were instructed to review their criteria to ensure that this scenario would not happen and that treatment or care were not delayed by uncertainty over funding responsibilities.

A number of other important principles were established by Grogan, one being the requirement of PCTs to assess all the individual's relevant needs rather than only their nursing needs. A further principle clarified the interaction between continuing healthcare and the registered nursing care contribution (RNCC). In all cases decision makers should establish whether an individual was eligible for continuing healthcare before considering which RNCC banding to apply to their care.

Pearce Ombudsman Case, 2007

Mike Pearce was forced to sell the family home to fund his mother's care fees after she was deemed ineligible for continuing healthcare. His mother suffered with Alzheimer's disease and

required full assistance with all activities of daily living. After a 5 year battle with Torbay PCT resulting in one of the first continuing healthcare assessments using the new National Framework (at the time not finalised), the Ombudsman upheld his complaint and recommended Torbay PCT pay £50,000 in retrospective restitution.

The Boundary Between Health and Social Care

The boundary between health and social care is mainly determined by the National Assistance Act (1948) and the NHS Acts (2006). Both the Local Authority and NHS have responsibilities to *accommodate* older people, people who are ill and disabled people. This creates potential for overlap. To account for this overlap, section 21 of the National Assistance Act states that nothing in section 21 *authorises* or *requires* a Local Authority to make provision as a provider under the NHS Act.

Section 21 does not prevent a Local Authority from providing health services, but the health services it provides are limited to those that have not been authorised by the NHS Act, and so includes those health services that the NHS Act says it is not necessary for the NHS to have to provide. Of course this was never meant to mean that Local Authorities are duty-bound to offer all the health services that are not necessary for the NHS to provide. The Local Authority is still only allowed to provide health services that section 21 of National Assistance Act states it can *lawfully* provide.

And so in order to identify which of those services it can *lawfully* provide, the Court of Appeal developed the 'quantity and quality test'. The test clarifies that healthcare services can be provided by the Local Authority only if those services are:

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

The result of this quantity and quality test is that there is a legal possibility of a gap between the provision of healthcare on the one hand, and the provision of social care *together with incidental and ancillary healthcare* on the other. Services which fall into this gap are those that the NHS Act says the NHS is not required to provide but neither can they be considered ancillary or incidental to the accommodation, and so they cannot legally be provided by Local Authorities with a social care package. The Department of Health made provisions to ensure that this gap was not able to arise.

As a result, where a person's *primary* needs are not health needs, the NHS is still responsible for meeting their health needs if they are beyond the power of the Local Authority to provide. This could be provided for as a joint package of care where certain healthcare tasks are identified, managed and funded by the NHS. NHS-Funded Nursing Care is also designed to pay for those elements of a person's needs which must be carried out by a registered nurse, again where those needs are not *primarily* health needs.

NHS continuing healthcare criteria have been established to assess when a person's needs are *primarily* health needs, and therefore must be paid for by the NHS. The Department of Health created four key indicators or 'characteristics of need' which are nature, intensity, complexity and unpredictability. These key indicators are used in the 'test' to identify whether the *quantity* or *quality* of the care that a person requires is beyond the limit of a Local Authority's responsibilities.

Each of the key indicators may alone or in combination demonstrate that a person has a primary health need due to the *quality* or *quantity* of care that is required to meet their needs. This is why it is so important for multidisciplinary teams to assess in such detail, so that both the quantity (amount, frequency) and the quality (type, complexity) of care provision can be fully appreciated.

Another two statutory restrictions were introduced on the provision of health services by Local Authorities. Section 29 of the National Assistance Act prohibits Local Authorities from providing any services that are *required* to be provided by the NHS under the NHS Act. This section enables Local Authorities to provide a range of non-residential services, whilst at the same time prohibiting them from providing services that the NHS has a *duty* to provide. It does not, however, prevent them from providing services that the NHS has just been *authorised* to provide under the NHS Act. This is why it is of paramount importance to include a representative from the Local Authority in all continuing healthcare eligibility decisions. If the Local Authority representative believes that the person's healthcare needs fall into a category that cannot legally be provided by the Local Authority, even if they are not needs that the NHS has a *duty* to provide, the NHS must still take responsibility for providing them.

The second statutory restriction is found in section 49 of the Health and Social Care Act 2001. This prevents Local Authorities from providing nursing care by a registered nurse, and led to the introduction of the *registered nursing care contribution (RNCC)*, and more recently NHS-Funded Nursing Care (FNC). Of course, this only applies to services that are required to be provided by a registered nurse, it is not intended to mean that none of the work of a registered nurse can be provided by the Local Authority. The outcome of this was that Local Authorities were prohibited from providing nursing care which is *required* to be provided by a registered nurse.

The reality of these various legal tests and provisions is that NHS continuing healthcare is highly confusing and contentious not only for the general public but also for health and social care authorities who struggle to apply the criteria in a consistent manner. The National Framework was intended to take the legal tests regarding the boundary between health and social care and work them into a set of criteria and procedures that could be understood and applied by health and social care professionals, not by lawyers.

The key indicators of nature, intensity, complexity and unpredictability were introduced by the Department of Health as a way of bringing the legal tests into the health and social care world, so that health and social care professionals whose responsibility it was to apply the National Framework on a day-to-day basis would also be applying the 'quantity and quality' test.

However, the reality is that not only are the concepts and procedures within the National Framework difficult for health and social care authorities to apply fairly and consistently, but eligibility decisions are too often made without proper regard to the important legal tests that govern the criteria. Furthermore, it is generally understood within the legal community that the 'quality and quantity' test which was established in the Coughlan judgement and provided that Local Authorities should only fund *low-level* healthcare needs, has been significantly altered by the concept of a primary health need.

This is all further complicated by the confusion surrounding services that can and should be provided by the NHS. It is very difficult in practice to actually specify which health services are required and which are authorised, and interpreting the difference between health and social care limits is dependent upon the ability to identify services that the NHS can or *must* provide.

There is now a great deal of overlap between health and social care as joint-teams are established with a greater focus on achieving outcomes within the team than traditional health and social allegiances. Pooled NHS / social care budgets, the introduction of personal health budgets and joint-commissioning strategies have further blurred the traditional boundaries, although it should be noted that in many cases this has actually improved service-delivery. Conversely, in some localities there remain clear divisions between health and social care departments with significantly differing views as to where the dividing line between responsibilities lies, with positions sometimes becoming so entrenched as to require third-party mediation – often on a case-by-case basis and to the detriment of the person requiring the service.

Comparing Your Needs to those of Coughlan

The National Framework was developed by the Department of Health in accordance with the principles established by Coughlan and is therefore said to be 'Coughlan compliant'. All individuals who are assessed for continuing healthcare (since October 2007) must be assessed according to the criteria, procedures and principles set out within the National Framework. Unfortunately when it comes to *applying* the Framework, the complexities of the eligibility criteria and legal tests allow for a high degree of professional judgement and interpretation by decision makers, meaning that criteria are not always applied in a consistent manner.

For example, the '*Decision Support Tool for NHS Continuing Healthcare, November 2012 (Revised)*' states:

"Where there is:

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

This may also, depending on the combination of needs, indicate a primary health need and therefore careful consideration needs to be given to the eligibility decision and clear reasons recorded if the decision is that the person does not have a primary health need."

This implies that an individual who has been assessed as presenting with several Moderate levels of need within the 12 care domains *may* be eligible for continuing healthcare. Potentially, there is a substantial difference between an individual who presents with several Moderate levels of need and one that presents with 2 Severe levels of need (which according to the guidance should result in eligibility). This leaves significant room for individual interpretation and inconsistency in the application of the primary health need approach.

It is generally understood that should Coughlan be assessed under the National Framework today she would probably be assessed as presenting with some Moderate levels of need across the domains. Having worked with hundreds of individuals since the National Framework was introduced in 2007 we have never come across a case of an individual being awarded continuing healthcare who presents only with a handful of Moderate levels of need in the Decision Support Tool. This does not mean that there are no examples of individuals with similar needs being assessed as eligible for continuing healthcare, but such examples are evidently in the minority.

This means that whilst the National Framework may be 'Coughlan compliant' it is possible to *apply* it in such a way that is not Coughlan compliant. It is quite possible that if Coughlan were assessed today, she would not be eligible. Considering that the judge in the case of Coughlan concluded that she required services of a 'wholly different category' and put her care needs well outside those that could be provided by social services, this raises significant questions about the way in which continuing healthcare criteria are being applied across the country.

Everybody's care needs are different. It is important that your particular set of needs are assessed on their own merits rather than in comparison with Coughlan, or anybody else. However, it is equally important that Clinical Commissioning Group decision-makers apply the eligibility criteria in a way that is fair, consistent and in line with the principles established by Coughlan. If you feel that the criteria has not been applied correctly in your case, then we would recommend that you challenge the decision.

References

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Further Contact

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

Oxford House, 1600 John Smith Drive
Oxford Business Park South
Oxford OX4 2JY

Tel: 0345 548 0300

www.beaconhc.co.uk



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