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NHS continuing healthcare: basic rules and common pitfalls

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This short legal guide is based on a chapter of a book published by the author in April 2020 – details can be found in the Publications section of the website. The book amplifies the law and guidance, summarises many legal and ombudsman cases - and provides the evidence for various practices indicated in this guide. Both this guide, and the book, focus on the position for adults (18 or over) in England.

INTRODUCTION. NHS continuing healthcare (CHC) is a term applied to some NHS patients, whose needs have been assessed against certain rules.

If patients have this legal status, the NHS is responsible for meeting the assessed health and social care needs of the patient; this might be in their own home, in a care home or indeed in any other setting. The care provided must be free of charge. Whereas, if the patient is not eligible for NHS continuing healthcare, then much of their care – deemed to be "social care" – will be means-tested by local authorities (local councils). And the patient may have to use what savings they have, or even sell their home.

There is therefore a three-way potential conflict between (a) patient and family, (b) the NHS, and (c) local authorities that are responsible for social care. Because central government, over a long period of time, has quite deliberately left the rules less than clear, the potential for this conflict is greater than it otherwise might be.

The particular problem is that the legal line between what is health care and what is social care has been left particularly vague. Thus, it can be very difficult for patients, families and even health and social care practitioners to know what the rules are and how they should be applied.

In addition, there is very great pressure on budgets. Therefore, it is in the immediate financial interests of central government and of the NHS to re-categorise health care needs, and to call them social care needs instead.

And, likewise, it is in the interests of local authorities, financially, either to deny that a person has social care needs and to argue that they have health care needs instead - or to accept they do have social care needs, but (a) to minimise the quantity and quality of care provided, and (b) to mean-test and financially charge the person to the fullest extent legally allowed.

All this means that the risk of unfair, opaque and sometimes unlawful decision-making is increased and is much greater than it ought to be.

OVERVIEW. This guide sets out the basic rules underpinning NHS continuing healthcare (CHC) decisions made by NHS clinical commissioning groups (CCGs). In addition is reference to some of the pitfalls to be wary of.

Challenging decisions made by the NHS on the basis of the outline of the rules below is something which may need to be done, whether by the patient themselves, their family, or indeed the local authority (which must try to ensure it does not unlawfully provide services which the NHS has a duty to provide).

Normally the best way of doing so is to focus on the *decision-making process*, and the presence and quality of explanation and reasoning, rather than a direct attack on the *final decision* about eligibility for CHC. Which is why one needs to understand at least the basics of what that decision-making process should look like.

The following outline is drawn from the relevant regulations[1], the Care Act 2014 and from guidance including National Framework guidance, the Checklist, the Decision Support Tool and the Fast Track Pathway Tool – as republished and amended in 2018. They are available online.[2]

[1] NHS Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012.

[2] All published by the Department of Health in 2018: *National Framework for NHS continuing healthcare*. And: *Decision Support Tool*. And*: Checklist*. And*: Fast Track Pathway Tool*. They can all be found online: https://www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care#history. (Accessed on 5th August 2019).

THE OUTLINE BELOW covers the main legal, and quasi-legal, rules used to decide whether a person has a "primary health need" and so is legally eligible for CHC. The main elements of these rules, are as follows:

- **Main route to primary health need and CHC eligibility - using** the **following steps in order:**
- Referral to the NHS clinical commissioning group
- Checklist (screening tool)
- Decision Support Tool (main assessment tool, multi-disciplinary team)
- Nature, intensity, complexity, unpredictability (decision about these characteristics)
- Quantity and quality of care (decision needed using the legal terms: incidental, ancillary, nature)
- Primary health need (final decision)

- **Alternative end of life route to primary health need and CHC eligibility**
- Fast Track Pathway Tool (completed by appropriate clinician, based on a person having a rapidly deteriorating condition which may be approaching a terminal phase)

- **Funded nursing care (FNC) – when a person in a nursing home is not eligible for CHC**
  Small contribution by the NHS to nursing home fees, if a decision has first been taken that a person is not eligible for CHC

- **Legal and ombudsman cases**
- Decision-making about CHC eligibility must be informed by relevant legal and ombudsman cases. In particular, indicative cases in which patients were found to have been eligible for CHC.

- **Challenging decisions**
- Challenges by patients and their representatives (families)
- Disputes between the NHS and local authorities

PRIMARY HEALTH NEED represents the summit of the decision-making process. It is a legal term. Regulations state that the purpose of an eligibility assessment for CHC is to determine whether a person has a primary health need. If so, then they are eligible for CHC, which is defined as a package of care arranged and funded solely by the NHS.[3] The word solely means that the NHS

[3] NHS Responsibilities Regulations, rr.20, 21(5), (6), (7).

alone has the duty, so joint funding is not possible, once a patient has been accorded CHC statis.

Eligibility means that "the NHS will be responsible for providing for all of that individual's assessed health and associated social care needs, including accommodation, if that is part of the overall need".[4] This could be in any setting, hospital, care home, hospice or a person's own home.

The person will benefit from the health services themselves, which may not otherwise be available through the local authority, by way of social care, in the same quality or quantity. And benefit financially as well. This is because under section 1 of the NHS Act 2006, health care provision must, by definition, be free of charge.

If the person is not eligible for CHC, then they may have to pay very significant costs for what will be deemed social care needs, by using their savings and selling their home. If they have no or few financial resources of their own, or when those resources are depleted, local social services authorities must step in to fund the care.

REFERRAL, GETTING THINGS STARTED: initial referral to the NHS could be made by anybody but there a specific duty as well. Under the Care Act 2014, a local social services authority is assessing a person's social care needs, it must make a referral to the NHS - if it appears that the person may have CHC needs.[5] This is a low threshold; it just needs to be an appearance of possible need; likelihood or certainty that the person will be eligible for CHC is not required.

Local authorities do not, for various reasons, always do this, with the result that a person may be denied the opportunity of a CHC assessment. So, patients and families may sometimes need to remind and urge the local authority to do so by submitting a Checklist to the CCG. On receipt, the CCG should normally make a final decision about CHC eligibility within 28 days.

THE CHECKLIST IN most cases (not end of life: see below) is the first step toward possible eligibility for CHC. It is a screening tool that is completed to

[4] National Framework 2018, para 54.
[5] Care and Support (Assessment) Regulations 2014, r.7.

give the NHS an idea of whether to complete a fuller assessment. It is published as guidance by the Department of Health and, if a screening tool is to be used at all, regulations state that it must be the Checklist and no other. Patients, families and practitioners need to try to ensure that it is completed appropriately.

The Checklist is the gateway to that fuller assessment which involves use and completion of the Decision Support Tool (see below). Once the Checklist is received by the CCG, an overall decision about CHC eligibility should be made within 28 days.

The Checklist is meant to set a low threshold only. Meaning it should not be used stringently to exclude people from fuller assessment. It can be completed by a range of health and social care practitioners. Extensive evidence about the person's condition is not required. For a resident of a nursing home, the Checklist must be considered before an assessment for funded nursing care (FNC: see below) takes place.

Practices of CCGs which sometimes undermine the rules in guidance and regulations - and which are therefore challengeable – include:

- using other screening tools (sometimes referred to, for example, as a "health needs assessment" or the "5Qs"), particularly in hospital;
- not completing Checklists for hospital patients who are returning to their own homes (CHC eligibility is not dependent on setting);
- making arbitrary decisions not to complete a Checklist at all;
- giving no reasons or evidence at all for completing a negative Checklist;
- not involving families and not listening to the evidence they put forward;
- demanding excessive evidence at the Checklist stage;
- over-restricting the classes of practitioner from whom it will accept Checklists (thus choking off their flow);
- exceeding routinely the timescale of 28 days for of making decisions about eligibility following receipt of the Checklist,

- in respect of nursing home placements, assessing for funded nursing care (FNC) before applying the Checklist: this is the wrong way around and can profoundly and unlawfully affect the outcome,

- leaving Checklist referrals in an unmanned email box for months, for example, or otherwise unacknowledged.

DECISION SUPPORT TOOL (DST) comes at the next, the second, stage, if a person "gets through" the Checklist. The DST, published by the Department of Health, involves fuller assessment; regulations state that it must be used.

For patients, families and practitioners, it is crucial to know about the DST and to try to ensure that it is completed accurately and fully. The DST looks more closely, via a multi-disciplinary team, at the person's needs. It is used to score those needs in terms of a number of "domains" (for example, behaviour, cognition, continence, communication etc.).

The DST states that if a person is scored sufficiently highly, it is more likely that they will make it to the next stage (see immediately below) and be eligible for CHC. Even if they have not scored so highly, they may still be eligible, because the DST scoring is meant to be indicative only and not decisive.

The DST should not be used prescriptively, is not meant to supplant professional judgement, cannot directly determine eligibility and, crucially, is subordinate to law, since it is merely guidance. In other words, the DST is an assist to deciding about a primary health need; any final decision must be consistent with the test set out in legislation concerning quality and quantity of care (see below); and must have taken account of legal and ombudsman case law.

Practices of CCGs which can sometimes undermine the rules in guidance and regulations about the DST – and which are therefore challengeable - may include:

- not using a multi-disciplinary team at all or in any meaningful sense;

- not using practitioners knowledgeable about either the health condition or patient or both;

- not involving families, not listening to the evidence they are putting forward, sometimes undermining them, sometimes even intimidating them;

- downplaying evidence of need;

- doing assessments for funding nursing care (FNC) first, and never getting round to completing a Checklist (and then DST) at all;

- applying the DST differently (and arguably in discriminatory fashion) to people with learning disabilities;

- routinely rejecting the recommendations of the multi-disciplinary team and even rescoring the DST themselves;

- using the DST prescriptively and to determine eligibility directly.

NATURE, INTENSITY, COMPLEXITY, UNPREDICTABILITY. Guidance states that the DST functions as a tool, an indicator, to determine overall whether the *nature, intensity, complexity or unpredictability* of a person's needs are such as to indicate a primary health need and therefore eligibility for CHC.

According to the guidance, affirmation of any single one (not necessarily all) of these four characteristics may be sufficient to demonstrate the quality or quantity of care required (the answer to which will indicate whether there is a primary health need). The higher the score on the DST, the more straightforward will this decision be.

Although referred to in the guidance, these four terms do not occur in legislation. They represent a further tool, a help, for deciding the legal question about quantity or quality of care (see below). Therefore, they remain subordinate to that legal question and to the relevant legal (and ombudsman) case law.

Practices of CCGs which can undermine both law and guidance – and which are therefore challengeable - can include:

- insisting that all four characteristics be present (not appreciating that these four characteristics are conjoined by the word "or", not "and");

- stating that unpredictability must always be an ingredient;

- stating, almost absurdly, that once unpredictability is identified it becomes "predictably unpredictable" (!) and so not unpredictable at all;

- not involving families and not listening to the evidence they are putting forward, about how their relative's multiple needs interact and lead to complexity or intensity of need;

- stating that, because family carers do not keep formal care records, there is insufficient evidence of the patient's needs (without the CCG making an effort to gain that evidence; it is of course the CCG's duty to obtain the evidence, not the overwhelmed family carer's duty to keep meticulous records of care).

QUALITY AND QUANTITY of care comes next, and this question is of greater legal significance than the steps above, because this question is routed in law: in a landmark legal case and in regulations.[6]

The decision about nature, intensity, complexity or unpredictability – the characteristics set out in guidance – is meant to lead to a judgement about the quantity and quality of health and nursing care required. Another way of referring to quantity and quality would be to consider the scale and type of care required.

The quantity test is referred to in legal case law and in legislation, in cumbersome language, but nonetheless is all important. It is about whether the health and nursing services a person needs are, *considered as a whole*, "merely incidental or ancillary" in relation to (a) the provision of accommodation (care home placement) being arranged by social services, or (b) to anything else social services is doing for the person under the Care Act 2014. The words, incidental or ancillary, suggest something minor or peripheral.

If the health and nursing services are merely that, then the local authority can, legally, provide them; otherwise, the NHS must, under regulations, decide that a person has a primary health need and is eligible for CHC. In which case, the NHS becomes responsible, solely, for meeting the need.

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[6] *R(Coughlan) v North and East Devon Health Authority* [2001] Q.B. 213, para 30. And: NHS Responsibilities Regulations 2012, r.21

The quality test is referred to in legal case law and the regulations by the word "nature". It is about whether the health and nursing services required are, considered as a whole, of a nature beyond that which a local authority, whose primary responsibility it is to provide social services, could be expected legally to provide.

In other words, taking the quality and quantity tests together, are the health or nursing services required, taken as a whole, beyond the legal remit of social services? If so, the NHS must, under regulations, decide that a person has a primary health need.

However, whatever the outcome of this twofold test, a local authority is, anyway and separately, prohibited from providing registered nursing care, no matter how minimal it may be. This is a separate rule contained in section 22 of the Care Act 2014.

Practices of CCGs which can undermine the rules in law and guidance, include:

- failing to refer to quality and quantity at all and to the primary heath need test;
- failing to take account of the *Coughlan* legal case, from which these questions derive and are now found in regulations;
- failing to follow the those regulations which contain the quality/quantity test;
- using the Decision Support Tool prescriptively and narrowly, without wider consideration of the true legal test of eligibility.

FINALLY, IF THE health and nursing services required in their totality are either more than just incidental or ancillary (as described above) or are, in any case, of a nature beyond what is expected of social services, then the CCG must decide that the person has a primary health need. In which case it must also decide that the person is eligible for NHS continuing healthcare.

WELL MANAGED NEEDS. One of the commonest ways in which the above decision-making process is not followed is in the case of "well managed needs".

For instance, if a nursing home is currently meeting a person's needs, the legally incorrect assumption is made that FNC (see below) applies and consideration for CHC never takes place. This assumption breaches the rule that CHC consideration (Checklist and DST) must take place first. And ignores the fact that even if a person's needs can be met by registered nursing in a nursing home, that person could still be eligible for CHC if their needs were equivalent to those of the resident in the *Coughlan* case.

Department of Health guidance is clear: "well managed needs are still needs".[7]

END OF LIFE, nonetheless, commands a different decision-making route. The above decision-making process - the Checklist, Decision Support Tool, quality/quantity test - is by-passed.

Instead, if a registered medical doctor or nurse responsible for the diagnosis, treatment or care of a patient completes the Fast Track Pathway Tool (FTPT), then the patient will be eligible for CHC.[8] This tool is another piece of Department of Health guidance, use of which is prescribed in regulations.[9]

Completion of the FTPT is to confirm that the patient has a primary health need arising from a rapidly deteriorating condition and that the condition may be entering a terminal phase. Once it is completed, the CCG must decide that the person is eligible for NHS continuing healthcare and arrange provision without delay. If a person nearing the end of their life does not qualify via the Fast Track Pathway Tool, they may nonetheless still do so via the Checklist and Decision Support Tool process.

Practices of CCGs which can undermine the rules in law and guidance – and which are therefore challengeable - include:

- not using an appropriate nurse or doctor to complete the Tool;
- refusing to accept the Tool even though the legal requirements in the regulations have been adhered to;

[7] Decision Support Tool 2018, para 27.
[8] *Fast Track Pathway Tool for NHS continuing healthcare*. London: DH, 2018.
[9] NHS Responsibilities Regulations, r.21.

- using rigid timescales, contrary to guidance, of prognosis of death to govern eligibility;

- delaying provision until the person has died.

FUNDED NURSING CARE represents a further piece of the jigsaw.[10] It applies if a person fails to qualify for NHS continuing healthcare but is in a nursing home. In which case, they will normally qualify for Funded Nursing Care (FNC). This involves the CCG paying a weekly amount, currently £165.56, to the nursing home to cover the registered nursing care that the resident needs. This amount should then reduce what either a resident is paying to the home as a self-funding resident, or what the local authority is paying to the care home.

Assessment for funded nursing care can, legally, take place only after consideration has been given to whether a CHC assessment is required, using the rules above. This is significant.

As a matter of law, and as already noted above, FNC can apply legally only if a person's needs for health and nursing services are not beyond the legal remit of social services, in terms of the quantity and quality of care required. Having established this, social services cannot proceed. Local authorities anyway cannot fund FNC, because of the separate rule in the Care Act 2014 that they are not allowed to.

Many residents are in nursing homes because of a substantial need for registered nursing care and other health services – not merely a need for such services peripherally or which would have been within the remit of social services. This suggests that many residents, in practice awarded FNC, ought arguably at least, to be assessed as eligible for NHS continuing healthcare – even if their needs could be met by the provision of registered nursing care alone. As was the situation in the *Coughlan* case (see below), which established the CHC rules in the first place.

Practices of CCGs which can undermine the rules in law and guidance – and are therefore challengeable – include:

- considering and assessing for FNC first, before CHC has been considered;

[10] NHS Responsibilities Regulations 2012, r.21(2), (3).

- not understanding that even a need for registered nursing care alone can still mean that a person is legally eligible for CHC;

- awarding FNC to people with nursing needs on a par with those of patients in several indicative legal or ombudsman cases which called for CHC, including the all-important *Coughlan* legal case;

- ignoring the quantity/quantity (incidental/ancillary and nature) test.

Care homes sometimes do not reduce the overall fee once FNC is awarded, as they should; but instead increase it by the amount of the FNC. This means that self -funding residents sometimes suffer insult added to injury, being not only wrongly denied full CHC funding, but also the financial benefit of the "free nursing care" meant to be represented by FNC.

LEGAL AND OMBUDSMAN cases must be brought into the equation when the rules above are applied. Department of Health guidance makes clear that, when taking a decision as to whether somebody has a primary health need and is therefore eligible for CHC, the CCG must consider indicative legal or ombudsman cases.[11]

That is, those cases which indicated circumstances in which eligibility for NHS continuing healthcare should have been established. In which case it might be expected that such an outcome would be reached if another patient has the same or similar needs.

CCGs sometimes make decisions seemingly with either no reference to (or knowledge of) these legal and ombudsman cases, or even with an apparent determination to ignore them, contrary to the law (after all, legal cases represent law) and to the guidance. Failure to do this could be another potential ground of challenge therefore; not least because the courts have pointed out that nursing home residents, with needs at a level equivalent to the Pamela Coughlan in the *Coughlan* case, would quality for CHC.[12]

[11] National Framework 2018, para 157.
[12] *R(Grogan) v Bexley NHS Care Trust* [2006] EWHC 44 (Admin), para 51.

PATIENTS AND FAMILIES CHALLENGING DECISIONS. There are various ways in which a challenge can be considered. None is likely to be easy.

- **Local review by CCG**. The person or their representative can ask the NHS clinical commissioning group (CCG) to review the decision, using a local resolution procedure. "A key principle of the local resolution process is that, as far as possible, if the CCG does not change the original decision, the individual or their representative has had a clear and comprehensive explanation of the rationale for the CCG decision". Requests for review should be dealt with in a timely manner.[13]

- **Independent review panel: NHS England**. If the dispute has not been resolved through local resolution, the person can make a request to NHS England for an independent review of the decision, if they are challenging either the decision regarding eligibility for CHC – or the procedure followed by the CCG in reaching its decision.[14] If the challenge were about anything else relating to CHC, the normal NHS complaints process would have to be used instead.

- **Health Service Ombudsman**. Following the above reviews, the person could seek to take their challenge further to the Health Service Ombudsman.

- **Local Government and Social Care Ombudsman**. Sometimes CHC-related challenges involve the local authority, when it has arguably failed in its responsibilities. For instance, by not making a referral to the NHS as demanded by section 9 of the Care Act 2014, with the consequence that the person has had to pay for their own care (which should have been free through the NHS) and perhaps even not received the services their needs required.

- **Judicial review legal case**. In some circumstances, a person might seek to take a judicial review legal case against the CCG or even the local authority.

- **Members of Parliament, Councillors and the Press**. Sometimes, a less formal way of challenge is through a local MP or a local Councillor. The House of Commons Library has from time to time produced briefing documents for MPS about NHS continuing healthcare – suggesting that it is something that arises, since such briefing papers are aimed, amongst other things, at helping MPs support constituents. The most recent of these, published in 2018, notes the difficulties, lack of understanding and confusion inherent in the system of NHS continuing healthcare.[15] A further option is

[13] National Framework 2018, paras 194-195.
[14] National Framework 2018, para 196.
[15] See e.g. Powell T. *Background to the National Framework for NHS Continuing Healthcare*. Standard note: SN/SP/4643. London: House of Commons Library, 2011. AND: Powell, T. *NHS continuing healthcare in England*. Standard note: SN/SP/6128. London: House of Commons Library, 2014. AND: Powell, T; Mackley, A. NHS continuing healthcare in England. Standard note: SN/SP/6128: London: House of Commons Library, 2018.

to go the Press, something that can bear fruit, but can be an unpredictable and in any event intrusive option.

DISPUTE RESOLUTION BETWEEN NHS AND SOCIAL SERVICES.

Disputes about NHS continuing healthcare (CHC) are not necessarily confined to patients and their families challenging an NHS clinical commissioning group (CCG). They may also involve CCGs and local authorities disputing with each other the legal responsibility for meeting a person's needs. Regulations clearly envisage this, since they stipulate that a local authority and CCG must both agree a dispute resolution procedure between them.

The procedure applies to a CHC eligibility decision; or, where a person is not eligible for CHC, to the respective contribution that the local authority and CCG makes to a joint funded package of care.[16] The CCG must, in operating the dispute procedure, have due regard to the need to promote and secure the continuity of appropriate services for the person involved.[17]

[16] NHS Responsibilities Regulations, r.22(2). And: Care and Support (Provision of Health Services) Regulations 2014, r.4.

[17] NHS Responsibilities Regulations, r.22(3).