

**SOLICITORS**  
**FOR THE ELDERLY**

**NHS CONTINUING  
HEALTHCARE  
IN ENGLAND**

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# **1. INTRODUCTION TO NHS CONTINUING HEALTHCARE**

## **1.1 Responsibility of the NHS and local authority**

‘NHS continuing healthcare’ is the term used when the NHS is responsible for paying for all the care and support required for an individual with ongoing health care needs. Where an individual qualifies for NHS continuing healthcare the funding for the whole package of assessed care becomes the responsibility of the relevant Primary Care Trust (PCT) as opposed to the local authority’s social services department.

There is no strict definition between what type of care the NHS should fund and what the local authority should fund. This has been an issue of contention since the formation of the welfare state shortly after the Second World War.

The National Assistance Act 1948 and the National Health Service Act 1946 both came into force on 5<sup>th</sup> July 1948. The 1946 Act has since been repealed. The current statute is the National Health Service Act 2006. The legislation places responsibility on both the NHS and local authorities to accommodate ill, injured and disabled people, with little clarification on which public body should accept which responsibility.

The National Assistance Act 1948, s21 (8) specifies, that a local authority is not authorised or required to provide a service which the NHS is authorised or required to make. This is often referred to as, ‘the section 21(8) boundary’ which is the point at which a local authority is not permitted to provide services.

Over time the NHS has assumed longer-term responsibility for people with non acute but continuing health care needs. Following a decrease in the number of long stay hospital beds, many local NHS bodies passed the responsibility for care over to the local authority means-tested system. As this has affected more people, particularly service users who self fund their care, many have questioned the NHS’s responsibility in terms of providing care.

## **1.2 The Leeds’ Case**

The involvement of the Parliamentary and Health Service Ombudsman (the Ombudsman), who investigated numerous complaints, led to a significant number of ‘benchmark’ cases. The Ombudsman’s reports, although not legally binding, have provided clarification of many issues and steered the path for reform. The first of these notable cases concerned a complaint against Leeds Royal Infirmary (Case Number: E.62/93-94) in January 1994.

This involved a man who suffered a brain hemorrhage and was admitted to a neuro-surgical ward. He received surgery but did not fully recover. After 20 months in hospital he was in a stable condition but still required full time nursing care. His

condition had reached a stage where active treatment was no longer required but he was still in need of substantial nursing care, that could not be provided at home and which he would continue to need for the rest of his life. The NHS did not feel that it was their duty to continue to provide his care believing it should be funded by his personal assets as he no longer required specialist medical supervision.

The Ombudsman criticised continuing care statements which placed an '*over-reliance on the needs of a patient for specialist medical supervision in determining eligibility for continuing in-patient care*' and specifically referred to the fact that *this was not considered by the ombudsman in the Leeds case as an acceptable basis for withdrawing NHS support.*'

### **1.3 The Coughlan Judgment**

This was subsequently followed by the most important and notable Court of Appeal Judgment of *R v North and East Devon Health Authority ex-parte Coughlan* [2000] 3 All ER 850, during which the Court tried to define the s21 (8) boundary by reference to the quality and quantity of healthcare that is provided.

Pamela Coughlan was seriously injured in a road traffic accident in 1971. This left her tetraplegic; doubly incontinent, requiring regular catheterisation; partially paralysed in the respiratory tract, with consequent difficulty in breathing; and subject to the problems of immobility and to recurrent headaches caused by an associated neurological condition.

Until 1993, Miss Coughlan's care was the responsibility of the NHS in Newcourt Hospital. Following the Health Authority's decision to close Newcourt Hospital, Miss Coughlan and the other residents were moved to Mardon House with the promise that this would be their home for life.

In October 1998, the successor Health Authority (North and East Devon Health Authority) decided to withdraw services from Mardon House, close the facility and transfer the care of the residents including Pamela Coughlan to the local authority social services. Miss Coughlan and the other residents did not wish to move out of Mardon House and argued that the breach of promise was unlawful.

The arguments on the closure of Mardon House raised another legal point, about the respective responsibilities of the NHS and local authority for nursing care for people who were chronically sick and disabled. The Court of Appeal's judgment on this aspect has heavily influenced the development of continuing care policy and the National Framework for determining eligibility.

The Court considered where the line should be drawn between long-term care that is the legal responsibility of the NHS and the long-term care that is the legal responsibility of the local authority.

The key points are as follows:

- The NHS does not have sole responsibility for all nursing care. Local authorities can provide nursing services under section 21 of the National Assistance Act 1948, so long as the nursing care services are capable of being properly classified as part of the social services' responsibilities.
- No precise legal line can be drawn between those nursing services that can be provided by a local authority and those that cannot: the distinction between those services that can and cannot be provided by a local authority is one of degree, and will depend on a careful appraisal of the facts of an individual case.

As a very general indication as to the limit of local authority provision, if the nursing services are:

- a) merely incidental or ancillary to the provision of the accommodation that a local authority is under a duty to provide, pursuant to section 21; (**the quantity test**) and
  - b) of a nature that an authority whose primary responsibility is to provide social services, can be expected to provide **then** such nursing services can be provided under section 21 of the National Assistance Act 1948 (**the quality test**)
- Section 21(8) of the National Assistance Act 1948, excludes a local authority from providing services where the NHS has responsibility.
  - The services that can appropriately be treated as responsibilities of a local authority under section 21 may evolve with the changing standards of society.
  - Where a person's primary need is a health need, the responsibility is that of the NHS, even when the individual has been placed in a home by a local authority.
  - An assessment of whether a person has a primary health need should involve consideration not only of the nature and quality of the services required, but also of the quantity or continuity of such services.
  - The Secretary of State's duty under section 3 of (what is now) the National Health Service Act 2006 is limited to providing the services identified, to the extent that he or she considers necessary to meet all reasonable requirements: in exercising his or her judgment, the Secretary of State is entitled to take into account the resources available to him or her and the demands on those resources.
  - In respect of Pamela Coughlan, her needs were clearly of a scale beyond the scope of the local authority.

Although Pamela Coughlan's needs were of a 'wholly different category', her healthcare needs were very modest. Despite her obvious medical condition, she was

stable, with little need for NHS specialists, was intellectually active and able to live in a semi-independent setting.

### ***Coughlan: Follow Up Guidance***

Following the Coughlan judgment, the Department of Health issued further guidance (HSC 1999/180) to health authorities asking them to ensure that their criteria complied with the Coughlan judgment. The guidance also advised that past cases should be reassessed if criteria were found to be flawed. At this time, each local health authority set criteria locally.

#### **1.4 The 2001 Guidance**

No further guidance was issued by the Department of Health until June 2001 when 'Continuing Care: NHS and Local Councils responsibilities' (HSC 2001/015) was issued which required all 95 Health Authorities (as they were at the time) to agree a joint continuing health and social care eligibility criteria with local authorities. The guidance indicated the key issues to consider when establishing criteria however it did not indicate exactly how these issues should affect eligibility.

The 2001 guidance stated that the key issues to consider were:

- Whether the nature or complexity or intensity or unpredictability of the individual's healthcare needs (and any combination of these) requires regular supervision by a member of the NHS multidisciplinary team such as the consultant, palliative care, therapy or other NHS member of the team.
- Whether the individual's needs require routine use of specialist healthcare equipment under supervision of NHS staff.
- Whether the individual has a rapidly deteriorating or unstable medical, physical or mental health condition and requires regular supervision by a member of the NHS multi-disciplinary team.
- Whether the individual is in the final stages of a terminal illness and is likely to die in the near future
- A need for care or supervision from a registered nurse and/or GP is not, by itself sufficient reason to receive NHS continuing NHS healthcare
- The location of care should not be the sole or main determinant of eligibility. Continuing NHS healthcare may be provided in a hospital, nursing home, hospice or the individual's own home.
- Eligibility criteria, application or rigorous time limits for the availability of services by a health authority should not require a council to provide services beyond those they can provide under section 21 of the National Assistance Act 1948.

In April 2002, the 95 health authorities were replaced by 28 Strategic Health Authorities and 303 Primary Care Trusts (PCT). Each Strategic Health Authority was asked to set an eligibility criteria with the local authority and to ensure that the

criteria was in use by each PCT in their area by March 2003.

### **1.5 The Ombudsman's reports**

However, the Health Service Ombudsman published a report in February 2003 entitled 'NHS Funding for long term care' drawing attention to a significant number of complaints investigated regarding eligibility criteria used by health authorities during the period from 1996 to 2001. The report concluded that the health authorities were using over-restrictive eligibility criteria that were not in line with the Department of Health guidance or with the Coughlan Judgment.

The report highlighted the following: -

- Allowing health authorities to develop their own local criteria could lead to variations in eligibility across the country leading to a postcode lottery.
- Patients and carers were being left inadequately informed due to guidance procedures not being published alongside eligibility criteria.
- Patients were not being told (with reasons) why they did or did not meet the criteria
- There was a need to develop a clear, well-defined national framework
- There was a need to ensure staff had detailed guidance and procedures on the assessment of patients and the application of eligibility criteria.

The report also published the findings of four investigations into complaints about the way health authorities set and applied their eligibility criteria.

#### ***Case Number E208/99-00107 – Dorset Health Authority and Dorset Healthcare NHS Trust***

Mr X had advanced Alzheimer's disease and had similar care needs to Pamela Coughlan. The local health authority's criteria for eligibility was such that if a person was sufficiently ill to require NHS care, then it would be provided in a local hospital and the only time that they would fund a care-home bed was if there was no such available bed. In addition, the criteria in relation to dementia patients implied that only those who needed clinical management by a consultant would be eligible. The complaint that the criteria were unreasonably restrictive was upheld. The Ombudsman recommended that the local health authority should revise its criteria, then apply them to Mr X and, if he should have been eligible, compensate his estate. Government guidance and the Coughlan judgment established that just because Mr X needed care due to his disease, it did not follow that all his care had to be provided by the NHS. As Mr X's condition was degenerative, however, he was more likely to have become eligible as time went by. This is an important point for practitioners, as the decision of whether a person is eligible is not a once-and-for-all decision.

***Case Number E420/00-01 – Wigan and Bolton Health Authority and Bolton Hospitals NHS Trust***

Mrs N had suffered several strokes and, as a result, she had no speech, was deaf, partially sighted and had little comprehension. She was unable to swallow, requiring PEG tube feeding. She was almost completely immobile, and doubly incontinent. The decision was made that she did not meet the criteria for continuing care as she did not require constant supervision of the consultant and her nursing needs did not require specialist nursing/clinical intervention and could be provided in a nursing-home setting. The ombudsman said: “I cannot see that any authority could reasonably conclude that her need for nursing care was merely incidental or ancillary to the provision of accommodation or of a nature one could expect social services to provide.” As such, the complaint was upheld. The Ombudsman recommended that the trust should remind staff responsible for carrying out such assessments to record the basis of their decisions in the medical records and to clarify who is party to the eligibility decision.

***Case Number E814/00-011808 – Berkshire Health Authority***

Mrs Z, aged 90, had vascular dementia. She also had very challenging behaviour. After a fall in hospital, she could no longer walk. She needed full help with all activities of daily living with the exception of feeding. The health authority took the view that she did not meet the criteria for full NHS funding but, as she needed to be cared for in a specialist nursing home providing care over and above that which a general nursing home might provide, they would make a contribution to the cost of her care. The authority’s criteria were not altered in light of the Coughlan judgment and as such, the Ombudsman could not find that it was compatible with it. The criteria were very restrictive. The Ombudsman said that it was: “Very possible (but not entirely certain) that, if appropriate criteria had been applied, Mrs Z would have qualified for fully funded care at some point.” The complaint was upheld. It was recommended that the local health authority should revise its eligibility criteria, reconsider Mrs Z’s case in the light of the revised criteria, and compensate her estate if she should have been assessed as eligible for all or part of the period in question.

***Case Number E1626/01-02109 – Birmingham Health Authority***

Mrs R, aged 90, had suffered a severe stroke, which had left her immobile, incontinent and confused. She was paralysed on her left side. The local health authority’s criteria, which had not been revised in the light of the Coughlan judgment, provided that patients would be entitled to NHS funded continuing care when their health needs are so complex and difficult that they need skilled health-care staff to look after them around the clock. The criteria could be interpreted as meaning that a nurse had to be in attendance 24 hours a day without a break. This would have been more restrictive than the national framework. There are patients who do not need weekly reviews by a consultant or round-the-clock continual and intensive care by a skilled health-care person but whose needs for nursing care are

greater than could be regarded as merely incidental or ancillary to the provision of accommodation. The ombudsman said that, if Mrs R had been assessed on proper criteria, “she might (though it is not possible to be certain) have been deemed eligible”. In fact, Mrs R had suffered no significant financial loss because she had been kept in hospital as an in-patient until six days before her death as a result of the dispute. The complaint was upheld in part.

Consequently all Strategic Health Authorities were requested to establish a set of eligibility criteria for NHS continuing care and

- To take steps to identify cases since 1996 that may have been wrongly denied NHS funded care. It was not possible to investigate cases where the patient died before 1996 as this was the date from which written eligibility criteria, based on national guidance, became operative. Before 1996 there was no obligation to have written criteria.
- To undertake retrospective reviews of those cases.
- To make appropriate recompense to the person or their estate where NHS funding had been wrongly denied.

The retrospective reviews were to be completed by December 2003 however the task was much larger than anticipated and cases remained outstanding in March 2005.

### ***The Pointon Case-eligibility in own home***

In November 2003, the Health Service Ombudsman upheld a complaint made on behalf of Mr. Pointon (Case Number E.22/02-03).

Malcolm Pointon had advanced dementia. He had no mobility, was doubly incontinent, unable to feed himself and at times had problems swallowing. He had no speech and little comprehension. His visual perceptions were diminishing and at times he hallucinated and suffered panic attacks. He also had myoclonic jerks, fits and Parkinson’s rigidity. Mrs Pointon was caring for her husband at home after removing him from a nursing home due to his deterioration.

In February 2001, Mr Pointon was assessed for NHS continuing healthcare. Mrs Pointon had prepared a list of her husband’s problems, together with the care and strategies to deal with them. A third of the list contained psychological problems and the balance physical problems, however this was ignored in the discussion. The conclusion was that Mrs Pointon could manage on her own with one other person attending for short periods in the morning, lunchtime, teatime and bedtime. As Mr Pointon did not require a registered nurse to provide this care, it was considered to be social care – which would be means tested. Mr Pointon’s healthcare needs were being met by the district nurse visiting him three times a week.

Between January 2000 and June 2001, Mr Pointon had received respite care in a specialist NHS unit one week in five but this was stopped after his dementia became

too severe for the staff to deal with.

A further assessment was undertaken in August 2001. An extra carer was offered to replace Mrs Pointon for one hour in the morning, lunchtime and at bedtime and half an hour at teatime for 6 days every 5 weeks. This was illogical, as his care needs had increased.

In January 2002, a formal complaint was lodged with the Health Authority, as well as a request for the review of the previous decision that he did not qualify for NHS funded care in his own home and NHS funded respite. By March, when nothing had happened, a complaint was lodged with the Ombudsman.

In April 2002, the PCT requested a further assessment. A district nurse undertook the assessment but asked few questions. The criteria only allowed care to be provided in a care home or hospital. The decision was that although some of his care needs had been overlooked his condition had not deteriorated to the point where his needs were unpredictable or unstable, requiring frequent intervention or reassessment by a trained nurse during a 24 hr period. The test used was whether any given task was a nursing or non-nursing one was whether it was necessary to replace a carer with a qualified nurse.

The Ombudsman complaint was to be pursued. The family obtained a report from an independent consultant in dementia who confirmed that the dementia was at a terminal stage, could hardly be more severe and that he met the criteria for NHS continuing healthcare as his health condition was severe, complex and unpredictable. All his care were related to health needs as they arose directly from his brain disease. The level of care he was receiving in his own home was equal, if not superior, to the care he could receive in a long stay dementia ward. His care included complete physical care, dealing with perplexing behaviour, fits, finding ways of communicating, giving frequent reassurance and providing 100% vigilance. This was confirmed by a consultant geriatrician reporting for the PCT.

In November 2002, the PCT conceded that Mr Pointon qualified for NHS continuing healthcare but the cost implications meant that the PCT would only fund the care in a nursing home setting. The reason was that the only way they could provide adequate services was by paying an agency nurse, as the community based health services were inadequate. The health respite was agreed by way of direct payments. Mrs Pointon agreed to this but during the Ombudsman's investigations, the PCT unexpectedly agreed to fund the whole cost of the care.

The Ombudsman's conclusions and recommendations were as follows: -

- a) The assessment in February 2001, should have included medical input and should have taken note of the Coughlan requirement to judge both the amount and type of nursing care. With a patient in these circumstances whose mental and physical condition was inevitably going to deteriorate, it was short sighted not to explore the physical and psychological problems, with a view to the kind of support that would be required in the near future.
- b) The policy and eligibility criteria for dementia used to assess needs focused on the difficulties for behaviour, such as violence or risk, but did not provide for mood changes, delusions, hallucinatory experiences and visual/spatial difficulties, which are common problems with advanced dementia. The criteria for an individual with sensory and/or psychological disabilities appeared to be based on their physical needs and the requirements of individuals with illness, which required palliative care, ventilation and medical intervention. The criteria, although Coughlan compliant, did not comply with the relevant Department of Health Guidance, as they were focused towards acute care, and made no provision for psychological needs of an individual with a mental health problem.
- c) Proper consideration was not given to Mr Pointon's eligibility. They relied on inaccurate or inadequate information, failed to take account of relevant facts and took account of irrelevant factors in their assessment.
- d) They also failed to recognise that the standard of care provided by Mrs Pointon was equal to that which a nurse could provide and her preference to nurse him at home caused them to be penalised.

This case highlights the key to success in obtaining funding is firmly rooted in the quality of the assessment.

### ***Review, revision and restitution report***

The Department of Health subsequently undertook a further independent review, 'Continuing health care: review, revision and restitution' in December 2004, which looked at factors affecting the integration of eligibility criteria and the investigation and restitution process.

### ***The Ombudsman's follow up report***

The Health Service Ombudsman's follow up report in December 2004, gave an overview of the type of complaints received about the review process.

The report highlighted the need for clear and consistent national guidelines about who is eligible for funding, which are understandable to carers and professionals; accredited tools and good practice guidance to support the criteria; correct approaches to assessing needs and ensuring there are enough people with the correct skills and training to undertake assessments at local level.

The report also drew attention to the misconception about the distinction between NHS continuing health care and ‘free’ nursing care, funded by way of a payment from the PCT to the nursing care home, in respect of resident receiving nursing care provided by a registered nurse.

On 9<sup>th</sup> December 2004, the Department of Health announced it was developing a national consistent approach to assessment for fully funded NHS continuing care, what was to later become known as ‘The National Framework’.

The House of Commons, Health Select Committee published a report in April 2005 that supported the need for a single national eligibility criteria taking into account psychological and mental health as well as physical health needs. They also recommended that it should be underpinned by a national standard assessment and a single set of documentation to record the outcome, so that confusion caused by similarities in the then current guidance, issued for NHS continuing healthcare and NHS funded nursing care could be addressed.

#### **1.6 R (T, D & B) v Haringey London Borough Council**

In 2005, the High Court heard the case of *R (T, D & B) v Haringey London Borough Council* [2005] EWHC 2235. This concerned patients, who required, amongst other things, maintenance care of a tracheotomy (a tube in the throat). The tubes needed suctioning regularly and replacing, about once a week. If the tube was not suctioned or became stuck the patient could die within minutes. Patients in this condition could be cared for at home if their carers are trained to carry out the daily routines and cope with the emergencies that may arise.

The judge held that a local authority could not provide care of this type, as it was an NHS responsibility. In his opinion, the decisive factors were the ‘scale and type of nursing care’ and the purpose of the care – in this case it was ‘designed to deal with the continuing medical consequences of an operation, which if not met would give rise to urgent or immediate medical needs. The advice on management was being provided by a hospital and medically qualified persons provided the training.

#### **1.7 R (Grogan) v Bexley NHS Trust (2006) 9 CCLR 188**

Maureen Grogan suffered from multiple sclerosis, had dependent oedema with the risk of ulcers breaking out, was doubly incontinent, a wheelchair user and needed two people to move her. She also had some cognitive impairment. After her husband’s death, her health deteriorated further and she was admitted to hospital after a number of falls. On leaving hospital, Mrs. Grogan was transferred to a care home providing nursing care.

She was assessed for NHS continuing healthcare but was not considered eligible. Instead she was assessed as eligible for Registered Nursing Care Contribution

(RNCC). RNCC, was introduced in 2001, following the passing of the Health and Social Care Act 2001, payable by PCTs to nursing care homes in respect of residents who need nursing care provided by a registered nurse. Between 2001 and 2007 the sum payable was determined by the level of the resident's need for a registered nurse, split into three bands; low, middle and high. Mrs Grogan qualified for the middle band rate moving briefly into the high band between April and October 2004, and then back to the middle band.

Mrs Grogan argued she had wrongly been denied continuing care funding because the eligibility criteria used by Bexley Care Trust were not 'Coughlan compliant' and therefore her assessment was unlawful. Instead, they had applied a higher test than that set out by the Court of Appeal in the Coughlan Judgment to assess her eligibility. Furthermore, Mrs. Grogan maintained that the level of nursing needs identified in the RNCC medium and high bands (in which she had been placed) indicated a primary need for health care, which should be met by the NHS.

Assessors at Bexley Care Trust were only granting NHS continuing healthcare when a patient's needs were seen to exceed the criteria for the high band of RNCC. As the highest RNCC band included people in extremely serious conditions, needing constant nursing care, getting fully funded NHS care was almost impossible.

The High Court Judge ruled in favour of Mrs Grogan and found that due to lack of clarity in the Department of Health's 2001 guidance on setting eligibility criteria for continuing care:

1. Assessors had been led to believe that if a person's needs could be met by the RNCC then they were not eligible for NHS continuing healthcare.

2. Bexley Care Trust's eligibility criteria were fatally flawed and therefore illegal because:

- (i) The criteria did not properly identify the Coughlan 'Primary Health Need Test' which defines the limits of a local authority's responsibilities for healthcare; and
- (ii) Bexley Care Trust had linked NHS continuing healthcare eligibility to the RNCC bands.

The Judge criticised the Department of Health for failing to provide clear guidance and direction to the NHS in their 2001 guidelines for setting eligibility criteria.

The Judge set aside Bexley Care Trust's decision that Mrs Grogan did not qualify for NHS continuing healthcare and referred the question of her funding entitlement back to them for further consideration. There was no finding, or other indication, that Mrs Grogan met the criteria for NHS Continuing Healthcare.

The Grogan Judgment highlighted many of the issues that had been covered in the Coughlan Judgment seven years before, including:

- Any person whose needs are the same as, or exceed, those of Pamela Coughlan should be entitled to continuing health care funding.

- Who provides the service should not be a factor in the decision-making process as non-nursing staff such as health care assistants often carries out nursing tasks.
- When assessing a patient for eligibility for NHS continuing healthcare, the assessor should look at the totality of a patient's needs to see if they have a primary health need, and so qualify for funding.
- Local authority social services departments should also examine the totality of a patient's needs before agreeing to provide means tested services, to check that the services they are planning to provide are not beyond the legal scope of the local authority.

### ***Grogan follow up guidance***

In March 2006, the Department of Health responded to the Grogan judgment by publishing interim guidelines for Strategic Health Authorities (SHAs), PCTs and local authorities to follow until the National Framework was introduced.

The guidelines asked SHAs to review their local eligibility criteria and their application to check that they were in line with the findings of the Grogan judgment and to revise them, if necessary. They were asked, in particular to review the interaction between their policies on NHS continuing healthcare and RNCC to ensure that correct procedures were being followed.

### **1.8 The National Framework for eligibility**

In June 2006, the Department of Health issued its consultation document on the National Framework, which proposed:

- A single policy on who should receive NHS funding
- One nursing band rather than three in respect of RNCC
- A standard process for assessing eligibility

Restructuring of the NHS in October 2006 resulted in Strategic Health Authorities being reduced from 28 to 10 and PCTs from 303 to 152.

In June 2007, the National Framework for NHS continuing healthcare and NHS funded nursing care was published and implemented from 1<sup>st</sup> October 2007. It is supported by various tools and guidance:

- A 'Checklist Tool' to screen those who may be eligible for NHS continuing healthcare;
- A 'Fast Track Pathway Tool' for people who are rapidly deteriorating or terminally ill;
- A 'Decision Support Tool' (DST), to record the totality of care needs and provides an indication of eligibility;
- NHS continuing healthcare practice guidance (March 2010)

The National Framework was subsequently reviewed in July 2009, to fulfill a commitment to review it within 12 months of the original publication. The changes made during the review were relatively minor; primarily to distinguish features between the various bands of the Decision Support Tool. The changes to the National Framework came into force on 1<sup>st</sup> October 2009.

The revised National Framework continues to rely on concepts that were not thought to be of overarching value by the court in Coughlan such as ‘primary health need’ and ‘nature, intensity, complexity and unpredictability’ of a health need. These concepts do not appear in the legislation.

It is worthwhile to note that it is highly unlikely that any of Pamela Coughlan’s needs would be assessed as anything greater than ‘high’ with most falling below this level, meaning that she would not qualify for NHS continuing healthcare, even though the Court of Appeal found that her care needs were of a ‘wholly different category’.

### ***Supporting Directions***

The Secretary of State for Health, gave the following Directions, which underpin the National Framework, in exercise of his powers conferred by sections 8, 272(7) and (8) and 273(1) of the National Health Service Act 2006 and section 7A of the Local Authority Social Services Act 1970, making them mandatory for the NHS and local authority to follow:

- The NHS Continuing Healthcare (Responsibilities) Directions 2009
- The NHS (Nursing Care in Residential Accommodation) (England) Directions 2007 (as amended by 2009 Directions)
- The Delayed Discharges (Continuing Care) Directions 2009

### ***Problems with definitions***

There continues to be no simple legal definition clearly explaining the difference between a ‘healthcare need’ and a ‘social care need’, although in general terms it can be said that a health need is one related to the treatment, control or prevention of a disease, illness, injury or disability and the care or aftercare of a person with these needs (whether or not the tasks involved have to be carried out by a health professional)<sup>1</sup>.

A social care need can be described as one that is focused on providing assistance with activities of daily living, maintaining independence, social interaction, enabling the individual to play a fuller part in society, protecting them in vulnerable situations, helping them to manage complex relationships and accessing a care home or other supported accommodation<sup>2</sup>.

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<sup>1</sup> Paragraph 4.11 NHS Practice Guide March 2010

<sup>2</sup> Paragraph 4.11 NHS Practice Guide March 2010

Social needs are directly related to the services that a local authority have a duty to provide i.e. social work services, practical assistance in the home, home adaptations, visiting and sitting services, provisions of meals, etc<sup>3</sup>.

The National Framework describes ‘NHS continuing healthcare’ as a package of continuing care that is arranged and funded solely by the NHS<sup>4</sup>. A slightly different term is, ‘continuing care’ which is defined as ‘care provided over an extended period of time to a person aged 18 or over, to meet physical or mental health needs that have arisen as a result of a disability, accident or illness’<sup>5</sup>. It is recognised that an individual who needs ‘continuing care’ may require services from the NHS and/or from the local authority. Both the NHS and the local authority have a responsibility to ensure that the assessment of eligibility for continuing care and its provision take place in a timely and consistent manner<sup>6</sup>.

### *Assessments- an overview*

The local authority is under a duty to assess any person who appears to be in need of ‘community care services’<sup>7</sup>. Community care services may include residential accommodation for persons who, by reason of age, illness and disability, are in need of care and attention that is not otherwise available to them<sup>8</sup> as well as domiciliary and community based services to enable people to continue to live in the community.

The local authority is required to notify the relevant PCT if, while carrying out an assessment, it becomes apparent that the person has needs that may fall under the National Health Service Act 2006, and invite the PCT to assist in making the assessment<sup>9</sup>.

In addition to this if an NHS body is assessing a person’s needs and the assessment indicates a potential need for community care services that may fall within a local authority’s responsibilities they should notify the local authority and consider inviting it to participate in the assessment process<sup>10</sup>.

It is a requirement that eligibility for NHS Continuing Health Care must be considered prior to any consideration of eligibility for NHS funded nursing care<sup>11</sup>.

All NHS bodies must take reasonable steps to ensure that an assessment for NHS

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<sup>3</sup> Paragraph 4.11 NHS Practice Guide March 2010

<sup>4</sup> Paragraph 8 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care and Paragraph 1(2) NHS Continuing Healthcare (Responsibilities) Directions 2009

<sup>5</sup> “Illness” is defined under the National Health Service Act 2006 as including any injury or disability requiring medical or dental treatment or nursing.

<sup>6</sup> Paragraph 9 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>7</sup> s47 NHS and Community Care Act 1990

<sup>8</sup> s21 National Assistance Act 1948

<sup>9</sup> s47(3)(a) National Health Service and Community Care Act 1990

<sup>10</sup> Paragraph 17 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>11</sup> Paragraph 24 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

continuing healthcare is carried out in all cases where it appears that a person concerned may have a need for such care<sup>12</sup>. There is no limit on the setting which an NHS continuing package of support can be offered or on the type of service delivery<sup>13</sup>; as such assessments can take place in any setting.

### *Primary healthcare need*

Eligibility for NHS continuing healthcare depends on whether the person's primary need is a 'health' need. A 'primary health need' means that the nursing or other health services the person requires are such that they are either:

- 1) more than incidental or ancillary to accommodation that local authority social services is under a duty to provide<sup>14</sup> or,
- 2) not of a nature that local authority social services has the power to provide<sup>15</sup>

However, the National Framework indicates that this test has certain limitations, therefore a practical approach to eligibility is required, for example when a person is being cared for in their own home. Certain characteristics of need and their impact on the care required to manage them may help to determine whether the 'quality' or 'quantity' of care required is more than the limits of a local authority's responsibilities<sup>16</sup>.

If the PCT decides that the person has a primary health need it must also decide that the person is eligible for NHS continuing healthcare<sup>17</sup>. Deciding whether this is the case involves looking at the totality of the relevant needs<sup>18</sup>. Where the person is eligible, the NHS is responsible for providing for all of that individual's assessed needs – including accommodation, if that is part of the overall need.”<sup>19</sup> However, accommodation and the cost of running a home would not be part of the need if the individual were receiving NHS continuing healthcare in their own home.

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<sup>12</sup> Paragraphs 2(a) NHS Continuing Healthcare (Responsibilities) Directions 2009

<sup>13</sup> Paragraph 8 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>14</sup> Paragraph 26(a) The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>15</sup> Paragraph 26(b) The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>16</sup> Paragraph 28 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>17</sup> Paragraph 6 The NHS Continuing Healthcare (Responsibilities) Directions 2009

<sup>18</sup> Paragraph 25 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>19</sup> Paragraph 25 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

## **2 THE ROLE OF THE CONTINUING HEALTHCARE CO-ORDINATOR**

The relevant PCT has the responsibility for coordinating the whole assessment process until the eligibility decision is made. The PCT should identify an individual to carry out the co-ordination role.

This role includes: -

- Receiving and acting upon a referral for assessment of eligibility and ensuring consent has been given.
- Identifying and securing the involvement of the multi disciplinary team (MDT)
- Supporting MDT members to understand their role in the multi disciplinary assessment and completing the decision support tool (DST).
- Helping the MDT members to identify whether they need to undertake an updated or specialist assessment to inform completion of the assessment.
- Supporting the individual to play a full role in the eligibility consideration process, including ensuring they understand the process, have access to support and organising the overall process in a manner that maximises their ability to participate.
- Ensuring there is a clear timetable for the decision making process.
- Ensuring that the assessment and the DST processes are completed in accordance with the requirements in the framework and relevant responsibilities directions.
- Acting as an impartial resource to the MDT/individual on any policy or procedure questions that may arise.
- Ensuring the MDT's recommendation on eligibility is sent for approval through the decision making process in a timely manner.
- If applicable (depending on local arrangements) inform the individual of the eligibility decision in a timely manner and in accordance with the requirement of the framework.

The co-ordinator should not be one of the people responsible for making the final eligibility decision<sup>20</sup>.

The client should be informed of the decision immediately. It is not acceptable for the client to be waiting extended periods of time for decisions to be made or given about their future care/support needs<sup>21</sup>.

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<sup>20</sup> Paragraph 6.12 The NHS Continuing Healthcare Practice Guide March 2010

<sup>21</sup> Paragraph 6.13 The NHS Continuing Healthcare Practice Guide March 2010

### 3. KEY INDICATORS FOR A PRIMARY HEALTH NEED

An individual has a primary health need if, taking into account all of their needs, it can be said that the main aspects or a majority part of the care they require is focused on addressing and/or preventing health needs<sup>22</sup>.

A primary health need is not about the reason why someone requires care or support, nor is it based on his or her diagnosis; it is about their overall actual day-to-day care needs taken in totality. It is the level and type of needs themselves that have to be considered when determining eligibility for NHS continuing healthcare<sup>23</sup>.

The key indicators below demonstrate a 'primary health need':

**3.1 Nature** describes the particular characteristics of a person's needs (including physical, mental health or psychological) and the types of needs; the overall effects of those needs on the individual, including the type ('quality') of interventions required to manage them;

*In simple terms this could refer to the features of the particular condition which are unstable, intractable, involuntary, chronic or persistent, or the type of intervention needed to manage the condition.*

This concerns the 'quality' of the service, namely whether it is of a nature, which it can be expected, a local authority should provide. In Coughlan the Court of Appeal held that Mrs Coughlan's needs were of a wholly different category to that which could be provided by a local authority.

The Health Service Ombudsman also reached this conclusion in relation to Patient N v Wigan and Bolton Health Authority and Bolton Hospital NHS Trust (Case No. E.420/00-01) and also in the Pointon case, where the special skills required to nurse someone with advanced dementia were considered qualitatively to be of a nature that a local authority could not lawfully fund.

Questions that may help to consider this include: -

- How does the individual or practitioner describe the needs (rather than the medical condition leading to them), what adjectives do they use?
- What is the impact of the need on overall health and well-being?
- What type of intervention is required to meet the need?
- Is there particular knowledge/skill/training required to anticipate and address the need?
- Could anyone do it without specific training?
- Is the individual's condition deteriorating/improving?

<sup>22</sup> Paragraph 4.2 NHS Continuing Healthcare Guide March 2010

<sup>23</sup> Paragraph 4.3 NHS Continuing Healthcare Guide March 2010

- What would happen if these needs were not met in a timely way?<sup>24</sup>

**3.2 Intensity** both the extent (**‘quantity’**) and Severity (**‘degree’**) of the needs and the support required to meet them, including the need for sustained or ongoing care (**‘continuity’**);

*This may refer to a chronic condition, which requires a type and level of care to manage or maintain health. There may be related needs to help minimise risks or it may mean that aggressive behaviour could present a significant risk to self or others which requires regular assessment.*

In order to decide whether in practical terms the overall quantity of nursing care is merely ‘incidental and ancillary’ to the provision of social care (key test in relation to the volume of the service), the determination must be based on the assessment of need not the service. Reference to whether service is provided by a nurse, domiciliary care agency, family carer or neighbour is of very little relevance. For a local authority to fund healthcare, the primary assessed need must be for accommodation and/or social care. Health support does not have to be provided by a qualified nurse.

Questions that may help consider this include: -

- How severe is this need?
- How often is this intervention required?
- For how long is each intervention required?
- How many care workers are required to meet this need?
- Does the care relate to needs over several domains?<sup>25</sup>

**3.3 Complexity** is about the level of skill/knowledge required to address an individual need or the range of needs and the interface between two or more needs;

*A client’s needs might be complex as a result of the interaction of multiple symptoms or secondary effects. This may also refer to the extent of intervention required for a single condition. Multiple conditions, treatments and or symptoms may require urgent or timed intervention. If this were not provided the client would be at significant risk.*

Questions that may help consider this include: -

- How difficult is it to manage the needs?
- How problematic is it to alleviate the needs and symptoms?
- Are the needs interrelated?
- Do they impact on each other to make the needs even more difficult to address?
- How much knowledge is required to address the need(s)?

<sup>24</sup> Paragraph 4.7 NHS Continuing Healthcare Guide March 2010

<sup>25</sup> Paragraph 4.8 NHS Continuing Healthcare Guide March 2010

- How much skill is required to address the need(s)?
- How does the individual's response to their condition make it more difficult to provide appropriate support?<sup>26</sup>

**3.4 Unpredictability:** this relates to the degree to which needs fluctuate, creating challenges in managing needs, and the level of risk to the client's health if adequate and timely care is not provided. Someone with an unpredictable healthcare need is likely to have a fluctuating unstable or rapidly deteriorating condition.

*Includes physical, mental or psychological health and/or the behaviour that requires prompt intervention to manage the risks by a health professional or informed carer to manage the risk. This could also refer to a severe and continuous deteriorating physical condition resulting in a rapid dependency or short-term life expectancy. Timely intervention is required to manage symptoms, avoid deterioration or distress and minimise risk.*

Questions that may help to consider this include: -

- Is the individual or those who support him/her able to anticipate when the need(s) might arise?
- Does the level of need often change?
- Does the level of support often have to change at short notice?
- Is the condition unstable?
- What happens if the need isn't addressed when it arises?
- How significant are the consequences?
- To what extent is professional knowledge/skill required to respond spontaneously and appropriately?
- What level of monitoring/review is required?<sup>27</sup>

The key factor to be considered is not how or by whom the healthcare is delivered, rather it is about the level of healthcare needs that the individual has and whether they mean the care required is of a **quantity** or **quality** that indicates that the individual has a primary health need (as per the Pointon case).

In considering the criteria of complex, intense or unpredictable categories judgments need to be made in light of whether the primary need is for healthcare, rather than a social care need, e.g. where the need requires health professionals to instruct or train carers in procedures it is likely to be a health need. Conversely, where the need is that which a layperson could normally meet this is likely to be a social care.

Eligibility does not depend upon the person's condition being unstable or unpredictable: Mrs Coughlan's care needs were neither. However, if these factors are present, it is likely to be indicative of entitlement to NHS continuing healthcare.

<sup>26</sup> Paragraph 4.9 NHS Continuing Healthcare Guide March 2010

<sup>27</sup> Paragraph 4.10 NHS Continuing Healthcare Guide March 2010

Some clients may have a primary health need on the basis of one indicator alone, while another client may have a primary health need based on a combination of indicators because of the quality and/or the quantity of care required to meet the needs<sup>28</sup>. The totality of the overall needs and the effects of the interaction of those needs should be carefully considered.

There will be some circumstances where the quality or quantity of the individual's overall general nursing care needs will indicate a primary health need and therefore eligibility for NHS continuing healthcare<sup>29</sup>.

Any likelihood of an increase in needs in the near future or 'deterioration' in the health condition should be taken into account when considering eligibility<sup>30</sup>.

If it is likely that an increase in needs may occur before the next planned review of care this should be documented and taken into account as this may result in immediate eligibility for NHS continuing healthcare, otherwise it may result in the recommendation of an early review<sup>31</sup> as this could be indicative of complex or unpredictable needs.

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<sup>28</sup> Paragraph 28 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>29</sup> Paragraph 28 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>30</sup> Paragraph 29 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>31</sup> Paragraph 29 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

## 4. GENERAL PRINCIPLES OF AN ASSESSMENT

Access to assessment, decision-making and provision should be fair and consistent. There should be no discrimination on the grounds of race, disability, gender, age, sexual orientation, religion or belief or the type of health care needed<sup>32</sup>. The diagnosis of a particular disease or condition is not in itself a determinant of eligibility for NHS continuing healthcare<sup>33</sup>.

Assessments of eligibility should be organised so that the person being assessed and their representative understand the process, and receive advice and information that will maximise their ability to participate in informed decision making about their future care. Decisions and rationales that relate to eligibility should be transparent from the outset<sup>34</sup>.

The person should be offered the opportunity to have a family member, advocate or other representative present<sup>35</sup> and should play a central role in the assessment process<sup>36</sup>.

### 4.1 When to consider an assessment

An assessment for eligibility should be considered: -

- (i) On discharge from hospital and the client is not being offered rehabilitation or other NHS funded services that may lead to an improvement in the condition.
- (ii) If physical or mental health deteriorates significantly and the current level of care seems inadequate whether at home or in care.
- (iii) When, as a resident of a nursing care home, the nursing care needs are being reviewed (which should be done at least annually).
- (iv) If there is a rapidly deteriorating condition with an increasing level of dependency and the person may be approaching the end of their life.

In a hospital setting, an NHS Body must take reasonable steps to ensure that an assessment for NHS continuing healthcare is carried out in all cases where it appears to the body that the patient may have a need for such care. However the screening should only be completed once an individual's acute care and treatment has reached the stage where their needs on discharge are clear<sup>37</sup>. This should be in consultation with the relevant local authority<sup>38</sup>.

If the PCT wishes to use an initial screening process it must complete and use the NHS continuing healthcare checklist tool to inform that decision, inform the person in writing of the decision as to whether to carry out a full assessment and make a

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<sup>32</sup> Paragraph 34 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>33</sup> Paragraph 46 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>34</sup> Paragraph 35 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>35</sup> Paragraph 70 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>36</sup> Paragraph 51 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>37</sup> Paragraph 6.4 The NHS Continuing Healthcare Practice Guide March 2010

<sup>38</sup> Paragraph 54 The National Framework for NHS Continuing Healthcare and NHS funded nursing care

record of that decision<sup>39</sup>. The ‘Responsibilities Directions’ state that a PCT can choose not to use a screening tool generally or in individual cases and instead directly use the Decision Support Tool (DST) but alternative-screening tools cannot be used<sup>40</sup>.

In a community care setting it may be appropriate to complete a checklist: -

- As part of a community care assessment
- At review of a support package or placement
- Where a clinician such as community nurse, GP or therapist is reviewing a patient’s needs.
- Where there has been a reported change in an individual’s care needs
- In any circumstance that would suggest potential eligibility for NHS continuing healthcare<sup>41</sup>.

#### **4.2 Consent to be assessed**

The individual’s informed consent should be obtained before the start of the process to determine eligibility for NHS continuing healthcare<sup>42</sup>.

It should be fully explained to the person whether their consent is being sought for a specific aspect of the eligibility consideration process or the full process. An individual may withdraw their consent at any time in the process<sup>43</sup>. Should this occur they must have the consequences of the withdrawal of their consent carefully explained to them (i.e. the local authority cannot take responsibility for meeting needs that would be the responsibility of the NHS)<sup>44</sup>

#### **4.3 Principles of decision-making**

Decision-making rationale should not marginalise a need just because it is successfully managed: well-managed needs are still needs<sup>45</sup>. The same criteria and assessment should be completed for someone who has mental health needs and the assessment should, where relevant, include the opinion of a psychiatrist or other mental health professional.

Only where successful management of a healthcare need has permanently reduced or removed an ongoing need will this have a bearing on eligibility<sup>46</sup>.

PCTs may ask the Multi Disciplinary Team (MDT) to carry out further work on a DST if it is not fully completed or there is a lack of consistency between the

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<sup>39</sup> Section 2(4) NHS Continuing Healthcare (Responsibilities) Directions 2009

<sup>40</sup> Paragraph 6.2 The NHS Continuing Healthcare Practice Guide March 2010

<sup>41</sup> Paragraph 6.5 The NHS Continuing Healthcare Practice Guide March 2010

<sup>42</sup> Paragraph 36 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>43</sup> Paragraph 37 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>44</sup> Paragraph 37 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>45</sup> Paragraph 47 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>46</sup> Paragraph 47 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

evidence recorded in the DST and the recommendation made<sup>47</sup>. The PCT cannot refer a case back or decide not to accept a recommendation because it differs from the one they would have made based on the same evidence<sup>48</sup>. It is worthwhile checking this point, as some PCTs may alter the levels given in the DST with the effect that the person becomes ineligible. Financial reasons should never form part of the PCT's decision not to follow the recommendation<sup>49</sup>.

The reasons given for decisions on eligibility should not be based on:

- The person's diagnosis;
- The setting of care;
- The ability of the care provider to manage care;
- The use (or not) of NHS employed staff to provide care;
- The need for/presence of "specialist staff" in care delivery;
- The fact that a need is well managed
- The existence of other NHS-funded care; or
- Any other input-related (rather than needs-related) rationale<sup>50</sup>.

At each stage, decisions made and their rationale should be transparent and communicated clearly in writing.

#### **4.4 Panel decisions**

A panel may be used to ensure consistency and quality of decision-making<sup>51</sup>. The panel must not fulfil a gate-keeping function, nor should it be used as a financial monitor<sup>52</sup>.

Finance officers should not be part of a decision making panel<sup>53</sup>.

#### **4.5 Length of time to reach a decision**

It is important that the process of considering and deciding eligibility does not result in any delay to treatment or to appropriate care being put in place<sup>54</sup>.

The National Framework states that decision making on eligibility should take no longer than 28 days from receipt of a completed checklist (or other notification of potential eligibility for NHS continuing healthcare)<sup>1 55</sup> where;

- The PCT makes a decision that a person is eligible for NHS Continuing Healthcare, and
- it has taken longer than 28 days to reach this decision
- a local authority or the person has funded services whilst awaiting a decision

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<sup>47</sup> Paragraph 81 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>48</sup> Paragraph 81 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>49</sup> Paragraph 48 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>50</sup> Paragraph 49 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>51</sup> Paragraph 80 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>52</sup> Paragraph 80 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>53</sup> Paragraph 82 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>54</sup> Paragraph 48 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>55</sup> Paragraph 84 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

The PCT should make all reasonable efforts to ensure all the required information/participation is made available within 28 days<sup>56</sup>. Where there are valid and unavoidable reasons for the process taking longer than the indicated timescales this should be clearly communicated to the person and/or their carer or representatives<sup>57</sup>.

#### 4.6 Care pending a decision

Care must be provided whilst a decision on NHS continuing healthcare is awaited<sup>58</sup>. The person should not find himself or herself in a situation where neither the NHS nor the relevant local authority will fund care either separately or together<sup>59</sup>. No individual should be left without appropriate support because statutory bodies are unable to agree on respective responsibilities<sup>60</sup>.

Some individual's needs will fall within the remit of both the PCT and the local authority, for example

- (i) The local authority is providing services during the period in which a NHS continuing healthcare eligibility decision is awaited;
- (ii) It is identified that the person has some health needs that are not within the power of the local authority to meet; and
- (iii) Those health needs need to be met before the decision on eligibility is made<sup>61</sup>

If, at the time of referral for NHS continuing healthcare the person is already receiving a care package funded by the PCT or the local authority (or a combination of both) these arrangements must continue subject to any urgent adjustments needed to meet any changing needs of the person<sup>62</sup>.

If the client is not in receipt of a care package from the local authority or PCT (or both) then they may have urgent health or social care needs, which need to be met whilst the NHS continuing healthcare decision is awaited<sup>63</sup>.

The PCT must consider whether the individual's health needs are such that it would be appropriate to make services available to help meet them in advance of the NHS continuing healthcare eligibility decision<sup>64</sup>. The PCT must provide such health services to such extent, as it considers necessary to meet all reasonable requirements<sup>65</sup>.

Where the person needs community care services the local authority must assess the eligibility for these, including consideration of whether there is a need to provide

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<sup>56</sup> Paragraph 9 NHS Continuing Healthcare Refunds Guidance March 2010

<sup>57</sup> Paragraph 84 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>58</sup> Paragraph 65 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>59</sup> Paragraph 26 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>60</sup> Paragraph 6 NHS Continuing Healthcare Refunds Guidance March 2010

<sup>61</sup> Paragraph 4 NHS Continuing Healthcare Refunds Guidance March 2010

<sup>62</sup> Paragraph 3 NHS Continuing Healthcare Refunds Guidance March 2010

<sup>63</sup> Paragraph 5 NHS Continuing Healthcare Refunds Guidance March 2010

<sup>64</sup> Paragraph 4 NHS Continuing Healthcare Refunds Guidance March 2010

<sup>65</sup> Responsibilities under s.3 of the NHS ACT 2006

services urgently in advance of any assessment<sup>66</sup>. If the local authority identifies a need for health services under the NHS Act 2006 the local authority must contact the PCT to take part in the assessment<sup>67</sup>. The PCT must meet its responsibilities under NHS Act 2006, s3 pending the outcome of the NHS continuing healthcare decision<sup>68</sup>.

#### **4.7 ‘End of Life’ Care (Fast Track Pathway Tool)**

The purpose of the Fast Track Pathway Tool (FST) is to ensure that people with a rapidly deteriorating condition, and may be entering a terminal phase, with increasing level of dependency, are supported to be in their preferred place of care as quickly as possible. This should be carefully and delicately explained to the person<sup>69</sup>.

The use of the FST is compulsory in such cases and variations should not be used.

The FST can be used in any setting where an individual satisfies the criteria for the use of the tool and they require an urgent package of support in their preferred location. The setting is not the most important issue but rather that the individual concerned receives the support they need in their preferred place as soon as possible<sup>70</sup>.

Consent to the completion of the FST is required<sup>71</sup>. If the person cannot consent the appropriate clinician should make a best interests decision in accordance with the MCA 2005<sup>72</sup>.

This tool should be completed by an appropriate clinician<sup>73</sup> responsible for diagnosis, treatment or care who should outline the reasons why the person meets the conditions for the fast tracking decision<sup>74</sup>. This should be supported by a prognosis, however strict time limits are not relevant for end-of-life care and should not be imposed<sup>75</sup>. It is the responsibility of the assessor to make a decision based on the relevant facts of the person’s case<sup>76</sup>.

An appropriate clinician can be clinicians in voluntary and independent sector organisations that have a specialist role in end of life needs provided they are offering services pursuant to the NHS Act 2006<sup>77</sup>; or a registered nurse; or a person included in the register maintained under the Medical Act 1983, s.2<sup>78</sup>.

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<sup>66</sup> s.47 NHS and Community Care Act 1990 and Paragraph 5 NHS Continuing Healthcare Refunds Guidance March 2010

<sup>67</sup> s.47(3) NHS and Community Care Act 1990

<sup>68</sup> Paragraph 6 NHS Continuing Healthcare Refunds Guidance March 2010 and s.47(3)(a) NHS & Community Care Act 1990

<sup>69</sup> Paragraph 89 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>70</sup> Paragraph 5.12 NHS Continuing Healthcare Practice Guidance March 2010

<sup>71</sup> Paragraph 5.5 NHS Continuing Healthcare Practice Guidance March 2010

<sup>72</sup> Paragraph 5.6 NHS Continuing Healthcare Practice Guidance March 2010

<sup>73</sup> “Appropriate Clinicians” are those persons who are, pursuant to the NHS Act 2006 responsible for an individual’s diagnosis, treatment or care and who are medical practitioners

<sup>74</sup> Paragraph 85 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>75</sup> Paragraph 87 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>76</sup> Paragraph 87 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>77</sup> Paragraph 86 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>78</sup> Section 2(13)(a)(iii) NHS Continuing Healthcare (Responsibilities) Directions 2009

The 'Responsibilities Directions' make it clear that a PCT must accept and action the FST immediately where the tool has been properly completed in accordance with the criteria for the use of the tool<sup>7980</sup>. PCTs should have a process in place to enable care packages to be implemented quickly. This time period should preferably not exceed 48 hrs from receipt of the completed FST<sup>81</sup>.

A PCT should not require any additional evidence to support eligibility although additional information to help identify the support package required can be helpful<sup>82</sup>.

The person should not experience delay in receiving care while disputes over how the tool has been used are resolved<sup>83</sup>. There may be circumstances where PCTs receive a completed tool that appears to show that the individual's condition is not related to the criteria. In these circumstances the PCT should urgently ask the relevant clinician to clarify the nature of the person's needs and the reason for the use of the FST<sup>84</sup>.

There are no time limits specified and the decision to use the FST should not be based solely around an individual's life expectancy. The phrase 'rapidly deteriorating' should not be interpreted narrowly as only meaning an anticipated specific or short time frame of life expectancy. Similarly the phrase 'may be entering a terminal phase' is not intended to be restrictive to only those situations where death is imminent. Someone may be currently demonstrating few symptoms yet the nature of the condition is such that it is clear that rapid deterioration is to be expected before the next planned review. It may be appropriate to use the FST in anticipation of those needs arising and agreeing the responsibilities and actions to be taken once they arise, or to plan an early review date to reconsider the situation<sup>85</sup>.

No one who has been identified as eligible for NHS continuing healthcare through the Fast Track Process should have their funding removed without going through the usual review process set out in The National Framework<sup>86</sup>. Funding arrangements should remain in place until any disputes have been resolved through the agreed dispute procedure.

End of Life care can be provided in a variety of settings. The client's wishes and needs should be at the heart of this process. Good practice is currently supported through a National End-of-Life Care Strategy.

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<sup>79</sup> Paragraph 5.3 NHS Continuing Healthcare Practice Guidance March 2010

<sup>80</sup> Paragraph 88 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>81</sup> Paragraph 5.11 NHS Continuing Healthcare Practice Guidance March 2010

<sup>82</sup> Paragraph 5.9 NHS Continuing Healthcare Practice Guidance March 2010

<sup>83</sup> Paragraph 88 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>84</sup> Paragraph 5.9 NHS Continuing Healthcare Practice Guidance March 2010

<sup>85</sup> Paragraph 5.7 NHS Continuing Healthcare Practice Guidance March 2010

<sup>86</sup> Paragraph 88 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

## 5 SCREENING FOR NHS CONTINUING HEALTHCARE

### 5.1 The checklist procedure

The first step to ascertain eligibility requires the person to be screened using the NHS continuing healthcare checklist<sup>87</sup> (unless the FST is more appropriate<sup>88</sup>). The checklist contains domains of care needs, sub-divided into broad levels of needs, identified by the letters A-C. The purpose of this is to encourage proportionate assessments so that resources are directed towards those most likely to be eligible<sup>89</sup>.

The checklist can be used by a nurse, doctor, qualified health care professional or social worker<sup>90</sup> and they must be familiar with the National Framework guidance and the Decision Support Tool (DST)<sup>91</sup>.

All the domains on the checklist must be presented with a tick. If the person's needs meet or exceed the descriptions given, a full consideration for NHS continuing healthcare assessment is required. If the checklist indicates a need for full assessment the person may be offered further NHS funded services before carrying this out. A note should then be made to carry out the full assessment at a later date<sup>92</sup>. There is flexibility to receive a full assessment even if the person does not apparently meet or exceed all the indicated thresholds and they can request that a full assessment is carried out.

The checklist does not indicate that the person will be eligible for NHS continuing healthcare only that they are entitled to **consideration** for eligibility<sup>93</sup>. Whatever the outcome of the checklist the decision (including the reasons why the decision was reached) should be communicated clearly in writing to the person and their representative, as soon as is reasonably practicable<sup>94</sup>.

The PCT remains responsible for funding the appropriate care during this interim period<sup>95</sup>.

### 5.2 Who should be present when the checklist is completed?

The individual should be given reasonable notice of the need to undertake the checklist, which depends on the circumstances of the case. The amount of notice given should take into account whether the individual wishes to have someone present to act as an advocate for them or represent or support them, and the

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<sup>87</sup> Section 2(4)(a) NHS Continuing Healthcare (Responsibilities) Directions 2009 – The PCT must use this checklist, it cannot deviate to one of its own and Paragraph 60 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>88</sup> Paragraph 60 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>89</sup> Paragraph 60 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>90</sup> Paragraph 63 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>91</sup> Paragraph 63 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>92</sup> Paragraph 64 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>93</sup> Paragraph 61 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>94</sup> Paragraph 66 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>95</sup> Paragraph 64 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

reasonable notice required by the person providing that support. The individual together with any representative should normally be present at the completion of the checklist<sup>96</sup>.

### **5.3 What information should be given to the individual?**

- They should be informed in advance of the need to complete the checklist and the reason for this.
- Patient information leaflet on NHS continuing healthcare
- Opportunity should be given for an explanation of the NHS continuing healthcare process to the person and for dealing with any questions
- It should be made clear that completion of the checklist does not indicate that they will be eligible for NHS continuing healthcare
- Whatever the outcome of the checklist, the person should be provided with confirmation of the decision as soon as reasonably practicable.
- Written decisions should include the contact details and complaints process.
- Copy of the checklist together with a covering letter giving appropriate details for challenging the decision will be sufficient to constitute a written decision in most circumstances<sup>97</sup>.

### **5.4 Checklist domains**

Each domain is divided into three levels of need and a relative weighting is given to each level.

A full consideration of eligibility is required if there are:

- Two or more ticks in column A (high levels of need)
- Five or more ticks in column B; or one tick in A and four in B (moderate levels of need in five or more domains or one high and four moderate);

Or

- One tick in column A in one of the boxes marked with an asterisk (which carry a priority level of need) with any numbers of ticks in the other two columns (one high level of need in one of the four domains that carries a priority level).

Priority level is given to:

- Behaviour
- Breathing
- Drug therapies and medication: symptom control
- Altered states of consciousness

If the person's needs exceed description A for one of these categories, with a minimum of one tick in any other column, B or C they should have a full

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<sup>96</sup> Paragraph 6.6 The NHS Continuing Healthcare Practice Guide March 2010

<sup>97</sup> Paragraph 6.7 The NHS Continuing Healthcare Practice Guide March 2010

assessment.

## **5.5 What should happen once the checklist is completed?**

If full consideration is required the checklist should be sent to the PCT where the individual's GP is registered unless alternative arrangements have been made by the PCT. It should be sent in the fastest but most appropriate secure way, which can include email.

The PCT should then arrange for a case coordinator to be appointed who will ensure that a MDT member carries out an assessment and uses this to complete a DST.

Where a checklist indicates that a referral for consideration for NHS continuing healthcare is not necessary, it is good practice for the checklist to be sent to the relevant PCT for their information, as the individual may wish to request the PCT to reconsider the decision<sup>98</sup>.

## **5.6 What evidence is required for the completion of the checklist?**

The checklist is intended to be relatively quick and straightforward to complete. Therefore there is no requirement to submit detailed evidence with the checklist. However, the checklist requests practitioners to record references to evidence that they have used to support the statement in each domain. This will enable evidence to be readily obtained for the purposes of the MDT, if the person requires full consideration for eligibility.

A 'rationale for decision' box is also included in the checklist, to give an overall explanation of why the individual should be referred for a full assessment. An individual may be referred for a full assessment despite the fact that the completed domains suggest that their needs do not meet the levels required, and in this case a fuller explanation will be important.

Whether or not an individual is being referred for full assessment of eligibility, the completed checklist should give sufficient information for the individual and the PCT to understand why the decision was reached<sup>99</sup>.

If a person believes that they should be check listed for NHS continuing healthcare they should contact their PCT's continuing healthcare team to ask for someone to visit to complete the checklist. Where the need for a checklist is brought to the attention of the PCT through these routes, it should respond in a timely manner, having regard to the nature of the needs identified. In most circumstances it would be appropriate to complete a checklist within 14 calendar days of such a request<sup>100</sup>.

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<sup>98</sup> Paragraph 6.7 The NHS Continuing Healthcare Practice Guide March 2010

<sup>99</sup> Paragraph 6.9 The NHS Continuing Healthcare Practice Guide March 2010

<sup>100</sup> Paragraph 6.11 The NHS Continuing Healthcare Practice Guide March 2010

## 5.7 The checklist and hospital discharge

In 2003, legislation was passed to ensure patients ready for discharge, who are the responsibility of the local authority are assessed by social services and provision made for their community care needs within a short time frame. Failure to assess and put in place services results in the NHS body, fining the local authority for every day that the patient remains unnecessarily in a hospital bed. If the hospital is planning to discharge the patient under the Community Care (Delayed Discharges etc.) Act 2003 (the 2003 Act), they must consider if the patient requires an assessment for eligibility to NHS continuing healthcare to be carried out before commencing the process<sup>101102</sup>. More specifically, The Delayed Discharges (Continuing Healthcare) Directions 2009, paragraphs 2(1) and 2(2) provides that before the hospital gives notice to the local authority, it must take reasonable steps to ensure that an assessment for NHS continuing healthcare is carried out in all cases where it appears to the NHS body that the patient may have a need for such care<sup>103</sup>.

The local authority should usually be represented on the MDT completing the NHS continuing healthcare eligibility process. Therefore, where a person is found to be ineligible the local authority should be in a position to respond and action their responsibilities within a short timeframe<sup>104</sup>.

Patients should not be transferred directly to long-term residential care from an acute hospital ward unless there are exceptional circumstances. Such circumstances might include: -

- a) Those who have already completed a period of specialist rehabilitation, such as a stroke unit.
- b) Those who have had previous failed attempts at being supported at home.
- c) Those for whom the professional judgment is that a period in residential intermediate care followed by another move is likely to be unduly distressing<sup>105</sup>.

They must consult with the individual and where appropriate their carer when carrying out the assessment<sup>106</sup>.

Where the client is screened in hospital for eligibility and the checklist has indicated that a full assessment is required a decision can be made at this stage to provide other services such as intermediate care, rehabilitation or a package of care at home and then to carry out a full assessment at a later date. The PCT remains responsible for funding the care. The PCT should ensure a full assessment is carried out once it

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<sup>101</sup> Paragraph 7.1 The NHS Continuing Healthcare Practice Guide March 2010

<sup>102</sup> Section 2(2) The Delayed Discharges (Continuing Care) Directions 2009

<sup>103</sup> Paragraph 7.1 The NHS Continuing Healthcare Practice Guide March 2010

<sup>104</sup> Paragraph 7.1 The NHS Continuing Healthcare Practice Guide March 2010

<sup>105</sup> Paragraph 7.2 The NHS Continuing Healthcare Practice Guide March 2010

<sup>106</sup> Section 2(3) The Delayed Discharges (Continuing Care) Directions 2009

is possible to make a reasonable judgment<sup>107</sup>.

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<sup>107</sup> Paragraphs 56 & 57 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

## 6 THE FULL ASSESSMENT PROCESS

Establishing that the person's primary need is a health need requires a clear, reasoned decision, based on evidence from a comprehensive assessment that looks at all needs including the way in which they interact with one another<sup>108</sup>.

When the person is referred for a full assessment, regardless of where they are living, that PCT has responsibility for co-ordinating the whole process until the decision on funding has been made and a care plan agreed<sup>109</sup>.

The PCT should consult with the relevant local authority, which should provide advice and assistance to the PCT including any information from a community care assessment where it has been carried out<sup>110</sup>, including a comprehensive multi-disciplinary assessment of the person's health and social care needs, with person's knowledge and consent. The person should be supported in order to be involved in the assessment<sup>111</sup>.

Even if the client is not eligible for NHS continuing healthcare, the PCT and local authority should always consider whether the assessment has identified needs that require any action to be taken<sup>112</sup>.

### 6.1 The Multi-Disciplinary Team

A Multi-Disciplinary Team (MDT) should carry out the assessment. 'Multi-Disciplinary Team' is defined under paragraph 5(a) of The NHS Continuing Healthcare (Responsibilities) Directions 2009 as 'a team consisting of at least: -

- (i) two professionals who are from different healthcare professions, or
- (ii) one professional who is from a healthcare profession and one person who is responsible for assessing individuals for continuing care services under s.47 of the National Health Service and Community Care Act 1990".

National Health Service and Community Care Act 1990, s47 (as amended) states:

'(1) Subject to subsections (5) and (6) below, where it appears to a local authority that any person for whom they may provide or arrange for the provision of community care services may be in need of any such services, the authority: -

- (a) shall carry out an assessment of his needs for those services; and
- (b) having regard to the results of that assessment, shall then decide whether his needs call for the provision by them of any such services.

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<sup>108</sup> Paragraph 51 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>109</sup> Paragraph 67 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>110</sup> Paragraph 73 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>111</sup> Paragraph 70 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>112</sup> Paragraph 52 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

(2) If at any time during the assessment of the needs of any person under subsection (1)(a) above it appears to a local authority that he is a disabled person, the authority:

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(a) shall proceed to make such a decision as to the services he requires as is mentioned in section 4 of the Disabled Persons (Services, Consultation and Representation) Act 1986 without his requesting them to do so under that section; and

(b) shall inform him that they will be doing so and of his rights under that Act.

(3) If at any time during the assessment of the needs of any person under subsection (1)(a) above, it appears to a local authority: -

(a) that there may be a need for the provision to that person by such Primary Care Trust as may be determined in accordance with regulations of any services under the National Health Service Act 2006, or

(b) that there may be a need for the provision to him of any services which fall within the functions of a local housing authority (within the meaning of the Housing Act 1985) which is not the local authority carrying out the assessment,

the local authority shall notify that Primary Care Trust or local housing authority and invite them to assist, to such extent as is reasonable in the circumstances, in the making of the assessment; and, in making their decision as to the provision of the services needed for the person in question, the local authority shall take into account any services which are likely to be made available for him by that Primary Care Trust or local housing authority.

(4) The Secretary of State may give directions as to the manner in which an assessment under this section is to be carried out or the form it is to take but, subject to any such directions and to subsection (7) below, it shall be carried out in such manner and take such form as the local authority consider appropriate.

(5) Nothing in this section shall prevent a local authority from temporarily providing or arranging for the provision of community care services for any person without carrying out a prior assessment of his needs in accordance with the preceding provisions of this section if, in the opinion of the authority, the condition of that person is such that he requires those services as a matter of urgency.

(6) If, by virtue of subsection (5) above, community care services have been provided temporarily for any person as a matter of urgency, then, as soon as practicable thereafter, an assessment of his needs shall be made in accordance with the preceding provisions of this section.

(7) This section is without prejudice to section 3 of the Disabled Persons (Services, Consultation and Representation) Act 1986.

(8) In this section-

‘disabled person’ has the same meaning as in that Act; and

‘local authority’ and ‘community care services’ have the same meanings as in section 46 above’

The MDT must undertake an assessment of needs that is an accurate reflection of that person’s needs at the date of the assessment and use that assessment to complete the DST issued by the Secretary of State.<sup>113</sup>

## **6.2 The Decision Support Tool (DST)**

This is designed to make the decision process as consistent as possible and is more in depth than the checklist<sup>114</sup>, but is not an assessment in itself. It is a way of bringing together and applying evidence in a single practical format to facilitate consistent, evidence based decision-making regarding eligibility. The evidence and the decision making process should be accurately and fully recorded<sup>115</sup>.

### ***What are the elements of a good Multi-Disciplinary Assessment?***

An assessment that simply gathers information will not provide the rationale for any consequent decision; an assessment that simply provides a judgment without the necessary information will not provide the evidence for any consequent decision.

Assessment documentation should be obtained from any professional involved in the individual care and should be clear, well recorded, factually accurate, up to date, signed and dated<sup>116</sup>. Care should be taken to ensure that alternative approaches for MDT participation still enable the individual being assessed for fully participate in the process<sup>117</sup>.

The assessments help build an evidence base to highlight care needs. Often access to NHS continuing healthcare is denied as a result of wrong or insufficient information contained in the assessment about the nature of the needs. Evidence from risk assessments should be taken into account<sup>118</sup>.

As a minimum a good quality multi disciplinary assessment will be: -

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<sup>113</sup> Section 2(5) The NHS Continuing Healthcare (Responsibilities) Directions 2009

<sup>114</sup> This must be used in accordance with section 2(5)(a)(ii) and 2(5)(b) of The NHS Continuing Healthcare (Responsibilities) Directions 2009

<sup>115</sup> Paragraph 71 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>116</sup> Paragraph 8.2 The NHS Continuing Healthcare Practice Guide March 2010

<sup>117</sup> Paragraph 8.5 The NHS Continuing Healthcare Practice Guide March 2010

<sup>118</sup> Paragraph 77 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

- Proceeded by informed consent or an appropriate “best interests” decision.
- Proportionate to the situation i.e. in sufficient depth to enable well-informed judgements to be made.
- Person-centred, making sure that the individual and their representative(s) are fully involved, that their views and aspirations are reflected and that their abilities as well as their difficulties are considered.
- Informed by information from those directly caring for the individual.
- Holistic, looking at the range of their needs from different professional and personal viewpoints, and considering how different needs interact.
- Taking into account differing professional views and reaching a commonly agreed conclusion.
- Considerate of the impact of the individual’s needs on others.
- Focused on improving outcomes for the individual.
- Evidence-based providing objective evidence for any subjective judgement made.
- Clear about needs requiring support in order to inform the commissioning authority of an appropriate care package.
- Clear about the degree and nature of any risks to the individual (or others), the individual view on these, and how to best manage the risks<sup>119</sup>.

The Single Assessment Process for older people, the Care Programme Approach used for mental health patients, person-centred plans for people with a learning disability, and the Common Assessment Framework are not assessments but they represent the individual’s own view of their needs and desired outcomes. They can offer key evidence to be considered when completing both the assessment and the DST. Health action plans and health checks can also provide useful evidence<sup>120</sup>.

Effective assessment processes and documentation are key to making swift decisions on eligibility for NHS continuing healthcare. Potential sources of information/evidence include: -

- Health needs assessment
- Community care assessment
- Nursing assessment
- Individual’s own views of their needs and desired outcomes
- Person centred plan
- Carer’s view
- Physiotherapy assessment
- Behavioural assessment
- Speech and language therapy (SALT) assessment
- Occupational therapy assessment

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<sup>119</sup> Paragraph 8.2 The NHS Continuing Healthcare Practice Guide March 2010

<sup>120</sup> Paragraph 8.3 The NHS Continuing Healthcare Practice Guide March 2010

- Care home/home support records
- Current care plan
- 24/48hr diary indicating needs and interventions (may need to be a ‘good day’ and ‘bad day’ where needs fluctuate)
- GP information
- Specialist medical/nursing assessment (e.g. tissue viability nurse, respiratory nurse, dementia nurse etc)
- Falls risk assessment
- Standard scales (e.g. Waterlow score for pressure sores)
- Psychiatric/community psychiatric nurse assessment<sup>121</sup>.

This should also ensure that the full range of factors that have a bearing on the person’s eligibility are taken into account<sup>122</sup>.

The MDT should take into account the range and levels of need recorded in the DST and what this tells them about whether the individual has a primary health need. This should include consideration of the nature, intensity, complexity or unpredictability of the individual’s needs. Each of those characteristics may, in combination or alone, demonstrate a primary health need, because of the quality and/or quantity of care required to meet the individual’s needs<sup>123</sup>.

The framework makes it clear that an MDT should usually include both health and social care professionals, who are knowledgeable about the individual’s health and social care needs<sup>124</sup>.

### ***Risk assessments***

A good risk assessment will include listening and observation, talking to the individual and their carers to identify what risks they see and their proposed response to them in the context of their circumstances. This can also involve talking to other agencies and providers of services and then listing the key risk factors e.g. isolation, self-neglect, self-harm or aggression. It is also important to establish what a particular adverse occurrence might happen and to evaluate both the likelihood and the potential impact of this occurrence.

### ***The care domains***

The person’s needs should be recorded in twelve ‘care domains’, which are then sub-divided into low, moderate, high, severe or priority levels of need, depending on the domain<sup>125</sup>.

The completion of the DST should result in an overall picture of the individual’s

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<sup>121</sup> Paragraph 8.3 The NHS Continuing Healthcare Practice Guide March 2010

<sup>122</sup> Paragraph 74 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>123</sup> Paragraph IV Decision Support Tool

<sup>124</sup> Paragraph 8.4 The NHS Continuing Healthcare Practice Guide March 2010

<sup>125</sup> Paragraph 74 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

needs that captures the nature, complexity, intensity and/or unpredictability and therefore the quality and/or quantity (including continuity) of care required to meet the individual's needs<sup>126</sup>. All care domains must be completed, as low needs can add to the overall picture, influence the continuity of care necessary and alter the impact that other needs have on the individual<sup>127</sup>.

A priority level demonstrates a primary health need<sup>128</sup> and is only given to four domains – behaviour; breathing; drug therapies and medication: symptom control and altered states of consciousness.

The 12 care domains are<sup>129</sup>:

- **Behaviour** (e.g. dementia/depression and the behaviours/treatments relating to these)(no need - priority)

This is a complex area to categorise, and maybe difficult to manage.

*Challenging behaviour includes but is not limited to: -*

- *Aggression, violence or passive non-aggressive behaviour*
- *Severe disinhibition (lack of restraint including disregard for social conventions, impulsivity, poor risk assessment)*
- *Intractable noisiness or restlessness*
- *Resistance to necessary care and treatment*
- *Severe fluctuations in mental state*
- *Extreme frustration associated with communication difficulties*
- *Inappropriate interference with others*
- *Identified high risks of suicide*

If the client has serious behavioural issues then a specialist will usually need to make the assessment.

- **Cognition** (how does the client understand and process information (no need - severe)

This may apply to individuals with learning difficulties or degenerative disorders that place them at risk of self-harm, neglect or exploitation again an appropriate specialist should be involved where cognitive impairment is indicated.

The National Framework refers to the application of the core principles of the Mental Capacity Act 2005,s1 in relation to a person's capacity.

- **Psychological and emotional needs** (no need - severe)
- **Communication** (is the client able to express their needs? (no need - high)
- **Mobility** (can client walk/move without support) (no need - severe)

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<sup>126</sup> Paragraph 75 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>127</sup> Paragraph 33 of the Decision Support Tool

<sup>128</sup> Paragraph 77 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>129</sup> Paragraph 74 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

Where mobility issues are indicated, a moving and handling and falls risk assessment should be undertaken as part of the assessment process (National Service Framework for Older People 2001, paragraph.6.14)

- **Nutrition** – food and drink (what care does client need to ensure they receive adequate levels of these?) (no need - severe)
- **Continence** – urine and bowel (including the management of incontinence. (no need - high)
- **Skin** – tissue viability and risk of pressure sores (no need - severe)

A wound assessment chart or tissue viability assessment should be undertaken if there is any evidence of wounds. A skin condition is any condition that affects or has the potential to affect the integrity of the person's skin.

- **Breathing** (no need - priority)
- **Drug therapies and medication** (including ability to manage its safe use) (no need - priority)

It is knowledge and skill required to manage the clinical need that is the determining factor where person is in a care home or at home.

- **Altered states of consciousness** (no need - priority)
- **Other significant care needs** (no need - severe)

This domain is to be used where the person has needs that are not easily categorised by the other care domains. In these circumstances the assessor must determine the extent and type of need and take that need into account<sup>130</sup>. The MDT should also assess the overall risk to both the person and to others, taking into account all the factors and record this in this care domain.

The score levels below indicate that the person meets the eligibility criteria for NHS continuing healthcare:

- A level of **priority** needs in any one of the four domains that carry this level.
- A total of two or more incidences of identified **severe** needs across all care domains.

Indicate a clear recommendation of eligibility to NHS Continuing Healthcare

Or if there is:

- One domain regarded as severe, together with needs in a number of other domains, or
- A number of other domains with high and/or moderate needs<sup>131</sup>.

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<sup>130</sup> Paragraph 76 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>131</sup> Paragraph 32 of the Decision Support Tool

This may well also indicate a primary health need. In these cases, the overall need, the interaction between different needs in different domains, and the evidence from risk assessments should be taken into account.

The primary health need must be based on what the evidence indicates about the nature/complexity/intensity/unpredictability of the individual together with consideration of the limits of the local authority's responsibilities.

If needs in all domains are 'no need' this would indicate ineligibility and if all are 'low' needs this is likely to indicate ineligibility<sup>132</sup>.

When completing the DST the following should be noted:

- All sections of the DST must be completed<sup>133</sup>.
- It is best practice that all care domains should be completed on the same day<sup>134</sup>.
- The team should use the assessment evidence and their professional judgment to select the level that most closely describes the person's needs<sup>135</sup>.
- The individual's needs should not be placed between levels. If it proves difficult to choose between two levels, the higher level should be selected and the reasons for the differences of opinion recorded<sup>136</sup>.
- Interactions between needs should be considered as appropriate<sup>137</sup>. Justifications of each particular level in a domain must be given in the available space on the DST. The needs must be described in measurable terms and supported with appropriate and validated assessment tools<sup>138</sup>.
- Needs not covered by one of the eleven specific care domains should be recorded in the twelfth care domain and taken into account when making an eligibility decision.<sup>139</sup>
- Needs should not be marginalised because they are successfully managed. Well-managed needs should be recorded as they are still needs<sup>140</sup>.
- Where needs are being managed via medication (whether for behaviour or for physical health needs). These should be reflected in drug therapies and medication domain<sup>141</sup>.

It is crucial that the MDT have a face-to-face meeting (including with the individual and/or their representative) to have a discussion about the correct recommendation to be made<sup>142</sup>. The individual should be invited to be present when the DST is

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<sup>132</sup> Paragraph 33 of the Decision Support Tool

<sup>133</sup> Paragraph Vii of the Decision Support Tool

<sup>134</sup> Paragraph 20 of the Decision Support Tool

<sup>135</sup> Paragraph 22 of the Decision Support Tool

<sup>136</sup> Paragraph 22 of the Decision Support Tool

<sup>137</sup> Paragraph 24 of the Decision Support Tool

<sup>138</sup> Paragraph 28 of the Decisions Support Tool

<sup>139</sup> Paragraph 31 of the Decision Support Tool

<sup>140</sup> Paragraph 29 of the Decision Support Tool

<sup>141</sup> Paragraph 30 of the Decision Support Tool

<sup>142</sup> Paragraph 8.5 The NHS Continuing Healthcare Practice Guide March 2010

completed and should be given sufficient notice for them to be able to arrange for a family member etc to be present<sup>143</sup>. The DST should note whether or not the client and/or representation were present and if not the reason why.

An MDT meeting should be as near to the individual's location as possible so they are able to be actively involved in the process<sup>144</sup>.

### **6.3 How the decision making process should work**

Whilst local conditions and local processes vary, the following elements are recommended as being core to achieving consistency:

- a) The co-ordinator should gather as much information as possible from professionals involved prior to the MDT meeting taking place, including agreeing where any new/updated specialist assessments are required prior to the meeting.
- b) The co-ordinator (or someone nominated by them) should explain the role of the MDT to the individual in advance of the meeting, together with details of the ways that the individual can participate. Where an individual requests copies of the documentation to be used this should be supplied.
- c) Information from the process and any additional evidence should be discussed within the MDT meeting to ensure common agreement on individual needs. Where copies of assessments are circulated to MDT members at the meeting, copies should also be made available to the individual if they are present.
- d) Relevant evidence (and sources) should be recorded in the text boxes preceding each of the domain levels within the DST and this information should be used to identify the level of need within that domain, having regard to the user notes of the DST. Having completed the domains the MDT, consideration should be given to what this information signifies in terms of the nature, complexity, intensity and unpredictability of the individual's needs. It is important that MDT members approach the completion of the DSTs objectively without any preconceptions that specific conditions or diagnoses do or do not indicate eligibility or fit a particular domain level without reference to the individual's needs.
- e) Depending upon local arrangements the MDT members may decide to reach the final recommendation on eligibility after the individual and their representative have left the meeting. However, the above gives clear expectations on their involvement in the wider process. If the MDT is to reach its final recommendation privately it is best practice to give the individual/representative an opportunity before they leave the meeting to state their views on what the eligibility recommendation should be in the

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<sup>143</sup> Paragraph 70 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>144</sup> Paragraph 8.6 The NHS Continuing Healthcare Practice Guide March 2010

light of the DST discussion.

- f) The MDT should then discuss, agree and record their recommendation, based on the concepts in d) above, providing a rationale which explains why the individual does or does not have a primary health need.
- g) The recommendation should then be presented to the PCT, who should accept this, except in exceptional circumstances. These circumstances could for example include insufficient evidence to make a recommendation or incomplete domains.
- h) If the PCT, exceptionally, does not accept the MDT recommendation it should refer the DST back to the MDT identifying the issues to be addressed. Once this has been completed the DST should be re-presented to the PCT who should accept the recommendation.
- i) The decision should be communicated in writing as soon as possible in an accessible format and language to the individual or their representative so that it is meaningful to them. They should also be sent a copy of the DST and information on how to ask for a review of the decision if the individual is dissatisfied with the outcome.

This whole process should usually be completed within 28 (calendar) days. This timescale is measured from the date the PCT receives the completed checklist indicating the need for full consideration of eligibility (or receives a referral for full consideration in some other acceptable format) to the date that the eligibility decision is made. However, wherever practicable, the process should be completed in a shorter time than this.

A copy of the DST should be made available to the individual together with an explanation as to the process for final decisions making by the PCT<sup>145</sup>.

#### **6.4 What does the DST recommendation need to cover?**

The DST should:

- Provide a summary of the individual needs in the light of the identified domain levels and the information underlying these. This should include the individual's own view of their needs
- Provide statements about the nature, intensity, complexity and unpredictability of the individual's needs
- Give an explanation of how the needs in any one domain may interrelate with another to create additional complexity, intensity or unpredictability.
- In the light of the above, give a recommendation as to whether or not the individual has a primary health need. It should be remembered that, whilst the recommendation should make reference to all four concepts of nature, intensity, complexity and unpredictability, any one of these could on their

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<sup>145</sup> Paragraph 19 of the Decision Support Tool

own or in combination with others is sufficient to indicate a primary health need<sup>146</sup>.

Where the outcomes of the individual care domains do not obviously indicate a primary health need, but the MDT is using a professional judgment to recommend that the individual does have a primary health need, it is important that the rationale for this is clear in the recommendation<sup>147</sup>.

The recommendation for eligibility for NHS continuing healthcare should be based on needs that are identified not based upon an individual specific condition or disease. Needs that give rise to eligibility can be from any condition or disease. The identification of a primary health need should not be prejudged without going through the proper process in each individual case<sup>148</sup>.

Once the MDT has agreed, their recommendations should be given to the PCT<sup>149</sup>. Only in exceptional circumstances, and for clearly stated reason, should the PCT not follow the MDT's recommendation<sup>150</sup>.

## **6.5 How should the decision be communicated?**

The individual should be informed in writing in an appropriate language or format as soon as possible. This should include the reasons for the decision and details of who to contact if they wish to seek further clarification or request a review of the decision.

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<sup>146</sup> Paragraph 8.10 NHS Continuing Healthcare Practice Guidance March 2010

<sup>147</sup> Paragraph 8.10 NHS Continuing Healthcare Practice Guidance March 2010

<sup>148</sup> Paragraph 8.10 NHS Continuing Healthcare Practice Guidance March 2010

<sup>149</sup> Paragraph 78 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>150</sup> Paragraph 80 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

## 7. WHAT HAPPENS IF THE PERSON IS ELIGIBLE?

The PCT should inform the person in writing, giving clear reasons and the basis on which the decision was made<sup>151</sup>. A copy of the completed DST should also be available. The PCT must provide a care package that it thinks is appropriate to meet the person's need.

It is normally the PCT responsible for the client's GP who will be responsible for funding the care<sup>152</sup>.

Care can be provided in a variety of settings including:

- A care home registered to provide personal or nursing care– the person should be given a choice about the location of care home, taking into account their needs and circumstances, however they have no right to choose.
- In a hospital – if the person is in the final stages of a terminal illness
- In their own home – depending on the type and level of care needed and whether their home is suitable or can be adapted, which should be offered, wherever appropriate<sup>153</sup>.

### 7.1 Choice of care provision

There will normally be a range of options available for support. The starting point for agreeing the package should be the individual's preference. However, the package of care provided will be what the PCT assess is appropriate for the individual's needs<sup>154</sup>.

The National Framework states:

*'When deciding on how their needs are met, the individual's wishes and expectations of how and where the care is delivered should be documented and taken into account, along with the risks of different types of provision and fairness of access to resources.'*<sup>155</sup>

If the person is living in a care home when the decision to grant NHS continuing healthcare is made the person will need to discuss with the PCT, whether they can continue to stay there. This is particularly relevant where the care home is much more expensive than the PCT would normally pay to meet their needs. However, the risks and benefits of moving the person, including the effect on their physical and mental health would need to be assessed before a decision is made to move them.

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<sup>151</sup> Section 2(10)(a) NHS Continuing Healthcare (Responsibilities) Directions 2009

<sup>152</sup> Regulation 3(7) of the National Health Service (Functions of Strategic Health Authorities and Primary Care Trusts and Administration Arrangements) (England) Regulations 2002 (S.I. 2002/2375) as amended by S.I. 2002/2548, 2003/1497, 2006/359 and 2007/559 ("the Functions Regulations")

<sup>153</sup> Paragraph 47 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>154</sup> Paragraph 100 The National Framework for NHS Continuing Healthcare and NHS funded nursing care

<sup>155</sup> Paragraph 33 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

The individual should be advised of all the options and the benefits and risks associated with each one. The model of support preferred by the individual may be more expensive than other options. PCTs can take comparative costs and value for money into account when considering the support to be provided but should consider the following factors: -

- The cost comparison has to be made on the basis of the genuine costs of alternative models. A comparison with the costs of supporting a person in a care home should be based on the actual costs that would be incurred in supporting a person with specific needs in the case and not on an assumed standard care home cost.
- Where a person prefers to be supported in their own home, the actual costs of doing this should be identified on the basis of the individual's assessed needs and desired outcomes. The willingness of family members to supplement support should also be taken into account, although no pressure should be put on them to offer such support.
- Cost has to be balanced against other factors in the individual case, such as the individual's desire to continue to live in a family environment.



#### **Gunter Case**

In the case of *Gunter v South Western Staffordshire PCT*, a severely disabled woman wished to continue living with her parents whereas the PCT's preference was for her to move into a care home. Whilst not reaching a final decision on the course of action to be taken, the court found that Article 8 of the European Convention of Human Rights had considerable weight in the decision to be made, that to remove her from her family home was an obvious interference with family life and so must be justified as proportionate. Cost could be taken into account but the improvement in the young woman's condition, the quality of her life in the family environment and her express view that she did not want to move were all important factors which suggested removing her from her home would require clear justification.

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If the person is unhappy about the plans for the location of their care these concerns should be put in writing to the care co-ordinator of the PCT requesting a meeting and detailing their reasons for objecting, for example, it is unreasonable if the suggested location was too far to allow family and friends to visit. However if the location is the only one able to meet the person's ongoing health needs, the PCT should fund this placement.

If the MDT feels that there is no health reason why the person's needs cannot be met from home but the needs cannot be met by existing community services, the PCT may commission specific resources to meet those needs at home.

## **7.2 ‘Topping-up’ for a higher cost care package<sup>156</sup>**

The funding provided by the PCT should be sufficient to meet the care needs identified in the care plan. Unless it is possible to separately identify and deliver the NHS funded element of the service, it will not usually be permissible for the person to pay for a higher cost service and/or accommodation<sup>157</sup>.

Where the person indicates a desire to pay for higher cost accommodation or services, the relevant PCT should liaise with them to identify the reason for the preference.

Where the need is identified as being for clinical reasons (for example a person with challenging behaviour wishes to have a larger room because it is identified that the behaviour is linked to feeling confined), consideration should be given as to whether it would be appropriate for the PCT to meet this.

When the person is already in a care home which is more expensive than what the PCT would usually meet for someone with their needs, the PCT should consider whether there are reasons why they should meet this cost such as the frailty, mental health needs or other relevant needs of the person are such that a move to other accommodation could involve significant risk to their health and well-being.

This may also arise where the person in an existing out of area placement becomes entitled to NHS continuing healthcare and this placement is at a higher cost than the responsible PCT would usually meet but is reasonable taking into account market rates in the locality. The PCT should consider whether there are circumstances that make it reasonable to fund the higher rate. This could be because of the location of the placement, such as its proximity to family members who play an active role in the individual’s life or they have strong social links to the area.

Where the PCT determines that circumstances do not justify the higher cost this decision should be taken in full consideration with the person concerned and put in writing with reasons given. If the person wishes to dispute this decision they need to do so through the NHS complaints process.

## **7.3 Responsibility when the person is supported in their own home**

### ***Care needs funded by the PCT***

The PCT remains financially responsible for all health and personal care services and associated social care services to support assessed health and social care needs and identified outcomes for that person, for example equipment provision, routine and incontinence laundry, daily domestic tasks such as food preparation, shopping,

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<sup>156</sup> Paragraph 11.16 NHS Continuing Healthcare Practice Guidance March 2010

<sup>157</sup> Guidance on NHS patients who wish to pay for additional private care, March 2009

washing up, bed-making, support to access community facilities, etc (including additional support needs for the individual whilst the carer has a break. However, they may also have additional community care needs, which the local authority needs to address, such as assistance with property adaptation.<sup>158</sup>

### ***Equipment***

The person should have access to local equipment on the same basis, as any other patient of the PCT. PCTs should make appropriate arrangements to meet these needs. PCTs should have clear arrangements with partners setting out how equipment needs of those entitled to NHS continuing healthcare should be met, including referral processes and funding responsibilities.

### ***Adaptations***

PCTs should be aware of their responsibilities and powers to meet housing related needs for those entitled to NHS continuing healthcare: -

- (i) PCTs have general responsibilities under of the NHS Act 2006, s3(e) to provide such after-care services and facilities, as they consider appropriate, as part of the health service for those who have suffered from illness.
- (ii) PCTs may make payments in connection with the provision of housing to housing authorities, social landlords, voluntary organisations and certain other bodies under the NHS Act 2006, s.256 and s.257.
- (iii) PCTs have general authority to make payments to local authorities towards expenditure incurred by the local authority in connection with the performance of any local authority function that; has an effect on the health of any individual; has an effect on NHS functions; is affected by any NHS function; or are connected with any NHS function.
- (iv) Housing can form part of wider partnership agreements under the NHS Act 2006, s.75.

### ***Community care needs***

Local authorities may continue to have responsibilities to assess and provide community care services, under the NHS and Community Care Act 1990, s.47 and the Chronically Sick and Disabled Person Act 1970, s.2 for those in receipt of NHS continuing healthcare.

A reasonable division of responsibility, between local authorities and PCTs, should be negotiated locally, however PCTs should first consider whether the responsibility to meet a specified need lies with them as part of their NHS continuing healthcare responsibilities.

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<sup>158</sup> Paragraph 11.8 NHS Continuing Healthcare Practice Guidance March 2010

The person remains entitled to Disability Living Allowance or Attendance Allowance.

#### **7.4 Reviews and withdrawal of funding**

Eligibility for NHS continuing healthcare is not indefinite<sup>159</sup>. A review should be carried out after 3 months and then, on a yearly basis thereafter<sup>160</sup>. If the person's needs have stabilised or improved they may no longer be eligible. This should be made clear to the person and their representative at the outset.

If the person is assessed as no longer being eligible they can ask for a review of this decision, if it is felt that the assessment was not carried out correctly, such as they failed to take all the person's health needs into consideration or their health is deteriorating.

Only where successful management of a healthcare need has permanently reduced or removed an ongoing need will this have a bearing on NHS continuing healthcare eligibility<sup>161</sup>.

If the local authority is responsible for any part of the care, both the PCT and the local authority will have a requirement to review needs and the services provided. It would be beneficial for them to conduct a joint review<sup>162</sup>.

*'Neither the NHS or the local council should unilaterally withdraw from an existing funding arrangement without a joint reassessment of the individual about the proposed change of arrangement. Alternative funding arrangements should first be put in writing to the individuals by the organisation that is proposing to make such a change. If agreement cannot be reached upon the proposed change, the local disputes procedure should be invoked and the current funding arrangements should remain in place until the dispute has been resolved'.<sup>163</sup>*

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<sup>159</sup> Paragraph 50 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>160</sup> Paragraph 138 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>161</sup> Paragraph 47 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>162</sup> Paragraph 139 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>163</sup> Paragraph 143 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

## 8. DISPUTING THE DECISION

There are two stages involved in dealing with any requests for review: -

- (i) A local review process at PCT level, and
- (ii) A request to the Strategic Health Authority (SHA), which may then refer the matter to an independent review panel (IRP).

### 8.1 Principles of dispute resolution procedures

The key principles for dispute resolution procedures involving NHS continuing healthcare (including both local procedures and independent review panels) are:

- Gathering and scrutiny of all available and appropriate evidence, whether written or oral, including that from the GP, hospital (nursing, medical, mental health, therapies, etc), community nursing services, care home provider, local authority records, assessments, checklists, DSTs, records of deliberations of MDTs, panels, as well as any information submitted by the individual concerned;
- Compilation of a robust and accurate identification of the care needs;
- Audit of attempts to gather any records said not to be available;
- Involvement of the individual or their representative as far as possible, including the opportunity for them to contribute and to comment on information at all stages;
- A full record of deliberations of the review panel, made available to all parties;
- Clear and evidenced written conclusions on the process followed by the NHS body and also on the individual's eligibility for NHS continuing healthcare, together with appropriate recommendations on actions to be taken. This should include the appropriate rationale related to this guidance.

The decision rationale should not be based on:

- The person's diagnosis;
- The inputs currently being provided rather than the care needs;
- The setting of care;
- The ability of the care provider to manage care;
- The use (or not) of NHS-employed staff to provide care;
- The need for/presence of 'specialist staff' in care delivery;
- The existence of other NHS funded care; or
- Any other input-related (rather than needs-related) rationale<sup>164</sup>.

All parties involved should be able to view and comment on all evidence to be considered under the relevant disputes procedure. Where written records or other evidence are requested, the PCT or SHA making the request should ensure that those providing the evidence are aware that it will be made available to those involved in the IRP. Where, in exceptional circumstances, those providing written records place any restrictions on their availability to all parties, the position should be discussed with the chair of the relevant disputes resolution body. The chair should consider the most appropriate way forward to ensure that all parties can play a full and informed

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<sup>164</sup> Paragraph 154 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

role in the process<sup>165</sup>.

## **8.2 Joint dispute resolution process**

The NHS Continuing Healthcare (Responsibilities) Directions 2009, require PCTs and local authorities to have an agreed local process for resolving disputes between them on issues relating to NHS continuing healthcare eligibility and the NHS elements of joint packages<sup>166</sup>. If disputes relate to local authorities and PCTs in different geographical areas they should agree a dispute resolution process to ensure resolution in a robust and timely manner. This should include agreement on how funding will be provided during the dispute and arrangements for reimbursement to the agencies involved once the dispute is resolved<sup>167</sup>.

No treatment should be refused or delayed due to uncertainty or ambiguity as to which PCT is responsible for funding a person's healthcare provision<sup>168</sup>. Disputes should not delay the provision of the care package<sup>169</sup>.

## **8.3 Non -eligibility at the checklist stage**

When a person wishes to challenge a checklist outcome they should contact the relevant PCT, using the contact information supplied with the written decision. They may ask for the PCT to reconsider its decision and agree to a full assessment of eligibility (i.e. arrange for the DST to be completed).

The PCT should give this request prompt and due consideration, taking account all the information available, including any additional information from the individual or carer. The response should be given in writing, as soon as possible.

If the person remains dissatisfied they can ask for the matter to be considered under the NHS complaints procedure. Details of how to do this should also be included with the written decision.

At any stage the PCT may decide that another checklist should be completed or to undertake the full DST process<sup>170</sup>.

## **8.4 Initial review of concern**

Where a person and/or their representative expresses concern about any aspect of the MDT or DST process, the PCT coordinator should review the evidence provided and discuss this matter with them in order to seek to resolve their concerns. Where the concerns remain unresolved, these should be noted in the relevant parts of the DST

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<sup>165</sup> Paragraph 156 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>166</sup> Paragraph 161 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>167</sup> Paragraph 161 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>168</sup> Paragraph 162 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>169</sup> Paragraph 161 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>170</sup> Paragraph 10.2 The NHS Continuing Healthcare Practice Guide March 2010

so they can be brought to the attention of the PCT making the final decision<sup>171 172</sup>.

## **8.5 PCTs non -acceptance of MDT recommendation**

In the following exceptional circumstances, the PCT or panel may not accept a MDT recommendation regarding eligibility for NHS continuing healthcare:

- Where the DST is not completed fully (including where there is no recommendation).
- Where there are significant gaps in evidence to support the recommendation.
- Where there is an obvious mismatch between evidence provided and the recommendation made.
- Where the recommendation would result in either the NHS or local authority acting unlawfully.

In such cases, the matter should be sent back to the MDT for the relevant matters to be addressed. However, where there is an urgent need for care/support to be provided the PCT/local authority should make appropriate interim arrangements without delay<sup>173</sup>.

## **8.6 Refunds, including for delays and ex-gratia payments**

The PCT's decision remains in effect until the PCT revises that decision<sup>174</sup>. When a PCT accepts an IRP recommendation on NHS continuing healthcare eligibility, it is in effect revising its previous decision in light of that recommendation<sup>175</sup>.

Where the PCT has taken longer than 28 days from receipt of the completed checklist and found the person to be eligible, they should refund to the person or the local authority, the costs of the services from day 29 of the period, that starts on the date of receipt of a completed checklist (or other notification of potential eligibility) and ends on the date that the decision was made<sup>176</sup>.

The refund should be made, unless the PCT can demonstrate that the delay is reasonable, due to circumstances beyond its control, which could include:

- Evidence (for example, assessments/care records) essential for reaching a decision on eligibility has been requested from a third party and there has been a delay in receiving these records from them.
- The person or their representative has been asked for specific information or evidence or participation in the process and there has been a delay in receiving a response from them.
- There has been a delay in convening a MDT due to the lack of availability of a non-PCT practitioner whose attendance is key to determining eligibility

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<sup>171</sup> Paragraph 10.3 NHS Continuing Healthcare Practice Guidance March 2010

<sup>172</sup> Paragraph 8.9 NHS Continuing Healthcare Practice Guidance March 2010

<sup>173</sup> Paragraph 9.3 NHS Continuing Healthcare Practice Guidance March 2010

<sup>174</sup> Paragraph 14 NHS Continuing Healthcare Refunds Guidance March 2010

<sup>175</sup> Paragraph 14 NHS Continuing Healthcare Refunds Guidance March 2010

<sup>176</sup> Paragraph 8 NHS Continuing Healthcare Refunds Guidance March 2010

and it is not practical for them to give their input by alternative means such as written correspondence/telephone<sup>177</sup>.

Where the local authority has been providing community care services to the person, and subsequently the PCT revises its decision, the PCT should refund the local authority the cost of the care package, based on the gross cost from the date of their decision (or earlier if the decision was unreasonably delayed) that the person was not eligible, until the date that the revised decision comes into effect<sup>178</sup>.

Where the individual has been required to make financial contributions to the local authority, the refund should still be made to the local authority as the refund of contributions is a matter between the local authority and the individual. The local authority should refund any contributions made by the person in the light that it has been refunded on a gross basis by the PCT<sup>179</sup>.

Where the PCT has unreasonably delayed in reaching its decision and the person has arranged and paid for services directly during the interim period it should also consider making an ex-gratia payment for the period of unreasonable delay<sup>180</sup>. This would be to remedy any injustice/hardship suffered by the individual as a result of the incorrect decision<sup>181</sup>.

Ex-gratia payments must be made in accordance with guidance under Managing Public Money<sup>182</sup> which sets out under Paragraph 4.12.4 that:

*‘Where public services organisations have caused injustice or hardship, they should consider providing remedies that, as far as is reasonably possible, restore the wronged party to the position that they would have been in had matters been carried out correctly’.*

## **8.7 The local review process**

A request for review should be made in writing to the chief executive of the PCT to ask for the case to be reviewed by the PCT review panel, stating clearly that the person has a primary health need that fits the criteria for NHS continuing healthcare. Appendix A of this book contains a sample letter to the PCT.

Each PCT should agree a local review process, including timescales, which is made publicly available; a copy should be sent to anybody who requests a review of a decision. The local review process may include a referral of the case to another PCT for consideration or advice, in order to provide greater patient confidence in the

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<sup>177</sup> Paragraph 8 NHS Continuing Healthcare Refunds Guidance March 2010

<sup>178</sup> Paragraphs 11, 15 NHS Continuing Healthcare Refunds Guidance March 2010; NHS Act 2006, s256

<sup>179</sup> Paragraph 11 NHS Continuing Healthcare Refunds Guidance March 2010

<sup>180</sup> Paragraph 12 NHS Continuing Healthcare Refunds Guidance March 2010; NHS Act 2006, s2 (1) (b) and paragraph 15(1) Schedule 3

<sup>181</sup> Paragraph 17 NHS Continuing Healthcare Refunds Guidance March 2010

<sup>182</sup> Paragraph 13 NHS Continuing Healthcare Refunds Guidance March 2010

impartiality of the decision-making<sup>183</sup>.

There should be consistency between the panel deliberations and the recommendation/decision letter<sup>184</sup>.

If the person is not satisfied with the review by the PCT they or their representative should write to the PCT stating that they are not satisfied that the case has been adequately reviewed and ask for an independent review of the case. The letter asking for a review to the PCT must explain the reasons for disagreeing with the PCT's initial decision.

Once local procedures have been exhausted, the case should be referred to the SHA's IRP, which will consider the case and make a recommendation to the PCT. If using the local process would cause undue delay, the SHA has the discretion to agree that the matter should proceed direct to an IRP, without completion of the local process<sup>185</sup>.

## **8.8 The independent review by the Strategic Health Authority**

### ***Grounds for review***

The individual or their representative may apply to the relevant SHA for an independent review of the decision, if they assert: -

- The criteria has been wrongly applied for NHS continuing healthcare (or NHS- funded nursing care); or
- There is a dispute about the process used by the PCT to reach eligibility decision and recommendation to the SHA about its findings<sup>186</sup>.

The eligibility decision that has been made remains in place until the independent review has been held.

The IRP will not look at issues which should be dealt with using the NHS complaints procedure, including:

- The content of the eligibility criteria
- The type and location of services offered
- The content of any alternative care package offered
- The quality of treatment provided<sup>187</sup>

It would be very unusual for the SHA to refuse an Independent Review. The framework states that this can only be done if the SHA considers that, 'the

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<sup>183</sup> Paragraph 152 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>184</sup> Paragraph 155 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>185</sup> Paragraph 153 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>186</sup> Paragraphs 2 (a) & (b) Annex E, Paragraph 148 of The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care<sup>186</sup>

<sup>187</sup> Paragraph 4 Annex E of The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

individual falls well outside the eligibility criteria or where the case is very clearly not appropriate for the panel to consider'.<sup>188</sup> The SHA should give a full written explanation of the reasons for the refusal and the right to challenge this decision under the NHS complaints procedure.

### ***Need for comprehensive assessment***

An IRP should not proceed if it is discovered that the individual has not previously received a comprehensive assessment of needs and a determination of their eligibility for NHS continuing healthcare, including use of the DST or the FST, as appropriate. Where an IRP request is received in such circumstances, the SHA should refer the case to the relevant PCT and ask for an assessment of needs and a determination of the individual's eligibility for NHS Continuing healthcare to be carried out, if it appears that there may be a need for such care<sup>189</sup>.

### ***Representation***

IRPs have a scrutiny and reviewing role. It is considered not generally appropriate for any party to be legally represented at IRP hearings, although individuals may wish to be represented by family, advocates, advice services or others in a similar role, either by them attending the panel meeting or by submitting their views in writing<sup>190</sup>.

If the individual is unable to attend or they do attend they should be able to bring a representative/advocate along for support or to speak on their behalf<sup>191</sup>. The panel members will need to satisfy themselves that the views of the representative/advocate do accurately represent the person's views and there are no conflicts<sup>192</sup>.

If the individual chooses to have a legally qualified person to act as their advocate, that person would be acting with the same status as any other advocate nominated by the individual concerned.<sup>193</sup>

Other key health and social care professionals (including any care home manager etc) should be able to attend or submit their views to the panel<sup>194</sup>.

### ***Preparation for the Independent Review Panel***

The IRP should let you have the documents they will use to consider the client's case and ask for further information about their health needs. This information is generally only provided about a week before the hearing. It is advisable to prepare

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<sup>188</sup> Paragraph 11 Annex E of The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>189</sup> Paragraph 3 Annex E of The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>190</sup> Paragraphs 16 Annex E, 157 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>191</sup> Paragraph 17 Annex E of The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>192</sup> Paragraph 17 Annex E of The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>193</sup> Paragraph 2.6, Practice Guide

<sup>194</sup> Paragraph 16 Annex E of The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

written submissions as soon as possible.

It is important to make a strong case, either by a written submission or if by attending the review panel hearing. You will need to explain why you think the person is eligible. The best way to do this is to compare the person's health needs with the eligibility criteria and care domains of the DST. Appendix B gives an example of a written submission to the IRP.

### ***The Independent Review Panel***

Every SHA must maintain an IRP and give clear information about how it works and the areas it does and does not cover. A full breakdown of the IRP's procedures can be found in Annex E of The National Framework.

The panel hearing will: -

- Consist of 3 people
- Will normally include a nursing adviser
- Is relatively informal as part of a fact gathering and decision making process
- In private – the PCT and the client should be interviewed separately

The panel may recommend that the case be reconsidered by the PCT, addressing the previous problems with how the process was carried out or how the criteria were applied<sup>195</sup>. It may also recommend that on the evidence submitted to the panel that the client should or should not be considered to have a primary health need<sup>196</sup>.

A full record of the panel hearing should be kept and the person and any other people involved should receive a copy<sup>197</sup>.

### ***The Independent Review Panel decision***

The SHA should let the client and the PCT know the outcome of the review generally within 4 weeks. The decisions of the IRP are advisory but should be accepted by the SHA in all but exceptional circumstances<sup>198</sup>. The decision of the IRP should include a date from which funding should have been awarded.

If a PCT decides not to accept an Independent Review Panel's recommendation, it should explain this in writing to the client and the SHA giving reasons why<sup>199</sup>. The person, if dissatisfied, can pursue this through the NHS Complaints procedure<sup>200</sup>. If the original decision is upheld and the person is still not happy then the case can be referred to The Parliamentary and Healthcare Ombudsman<sup>201</sup>.

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<sup>195</sup> Paragraph 21(a) Annex E of The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>196</sup> Paragraph 21(b) Annex E of The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>197</sup> Paragraph 22 Annex E of The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>198</sup> Paragraphs 23 Annex E, 158 of The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>199</sup> Paragraph 24 Annex E of The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>200</sup> Paragraph 26 Annex E of The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>201</sup> Paragraph 159 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

## **8.9 The Parliamentary and Healthcare Services Ombudsman (PHSO)**

If there is still not a satisfactory decision regarding the entitlement to NHS continuing healthcare or if it was not agreed by the PCT for the case to be heard by an IRP, the person can make a complaint to the PHSO.

They are able to investigate:

- (a) Maladministration – poor administration or the wrong application of rules
- (b) Clinical judgment – an inappropriate action/decision made by a member of staff.

The complaint must be made no later than 12 months from the date when the local resolution process ended, although the PHSO has discretion to extend this time limit if considered reasonable.

It will normally be expected that the decision has already been investigated locally by the PCT and independently by the SHA before this stage, but there may be special circumstances when the person, their carers or representative can go directly to the PHSO, where there are problems with administration of the dispute. The PHSO is able to put pressure on the PCT/SHA to administer the complaint/review properly.

It is recommended that you call the helpline first to check that you have a case (0345 015 4033). Following this, the complaint should be made in writing, completing the standard complaint form and enclosing supporting evidence. This should include all correspondence and documentation, set out in chronological order with a contents list. It is important to clearly match your complaint to the scope of the PHSO's remit. The form is available from the following link: [http://www.ombudsman.org.uk/\\_data/assets/pdf\\_file/0018/3933/health-complaint-form-030810.pdf](http://www.ombudsman.org.uk/_data/assets/pdf_file/0018/3933/health-complaint-form-030810.pdf)

The PHSO may ask the PCT to review the case again, where omissions or errors are identified or they may also tell you to go through the NHS complaints procedure.

If they decide to investigate the complaint, they will contact all parties and request further evidence and information as necessary. If they decide not to investigate they will explain why in full detail.

Following the outcome of an investigation, a draft report is prepared and may be shared with all parties, pending it being finalised. Significant investigations are published.

## **8.10 Complaints (as opposed to reviews)**

All primary and secondary care trusts have a Patient Advice and Liaison Service (PALS) which will record the complaint, direct the complaint to the right department and provide support to resolve the complaint.

NHS bodies must follow ‘The Local authority Social Services and NHS Complaints (England) Regulations 2009’ in resolving complaints, and can work with local authorities where the complaint overlaps, and vice versa. The same complaint process applies to local authorities. The Regulations adopts a single local resolution approach, with the aim of resolving the complaint.

### ***The complainant***

A person can make a complaint on behalf of a person who has died<sup>202</sup> and can make a complaint on behalf of someone who cannot make the complaint due to their: -

- (a) Physical incapacity; or
- (b) Lack of capacity within the meaning of the Mental Capacity Act 2005<sup>203</sup>.

A representative can also make a complaint where the person to whom the complaint relates has requested them to act on their behalf<sup>204</sup>.

### ***Time limit to make a complaint***

Complaints must be made no later than 12 months after: -

- (a) the date on which the subject of the complaint occurred
- (b) the date on which the subject of the complaint came to the notice of the complainant<sup>205</sup>.

However the time limit shall not apply if:

- (a) the complainant had good reason for not making the complaint within that time limit; and
- (b) notwithstanding the delay it is still possible to investigate the complaint effectively and fairly<sup>206</sup>.

### ***The process***

(i) A complaint can be made orally, in writing or electronically i.e. by email<sup>207</sup>. Once a complaint is made it must be acknowledged within 3 working days<sup>208</sup>, either

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<sup>202</sup> S.5 (2)(a) The local authority Social Services and National Health Service Complaints (England) Regulations 2009

<sup>203</sup> s.5(2)(c)(i) & (ii) The local authority Social Services and National Health Service Complaints (England) Regulations 2009

<sup>204</sup> s.5(2)(d) The local authority Social Services and National Health Service Complaints (England) Regulations 2009

<sup>205</sup> s.12(1) The local authority Social Services and National Health Service Complaints (England) Regulations 2009

<sup>206</sup> s.12(2) The local authority Social Services and National Health Service Complaints (England) Regulations 2009

<sup>207</sup> s.13(1) The local authority Social Services and National Health Service Complaints (England) Regulations 2009

<sup>208</sup> s.13(3) The local authority Social Services and National Health Service Complaints (England) Regulations 2009

orally or in writing<sup>209</sup>. They must make a written copy of the complaint and the complainant must be provided with a copy of this<sup>210</sup>.

(ii) The complainant should be offered the opportunity of a face-to-face meeting to discuss the issue<sup>211</sup>. They should be able to agree a plan of action including definite timescales for when and how they will hear back about their complaint<sup>212</sup>.

(iii) The complaint must be investigated in a manner appropriate to resolve it speedily and efficiently<sup>213</sup>. The complainant should be kept informed as to the progress of the investigation<sup>214</sup> and should be asked about how they wish to be kept informed i.e. phone, letter, email or through a third party as a matter of courtesy.

### ***Timescale to resolve the complaint***

- The complaint should be finalised within 6 months from the day when the complaint was received<sup>215</sup>.
- If the investigation is not finalised within 6 months the complainant must be informed in writing of the reasons why<sup>216</sup>.
- A case lasting more than six months should be reviewed to ensure everything is being done to resolve it. There can be good reasons for a complaint taking more than 6 months to investigate.
- Once any investigation is completed the complainant should receive a written response from the person handling the complaint explaining the outcome and what action has been taken<sup>217</sup>.

### ***The complainant's rights***

- Have their complaint dealt with efficiently<sup>218</sup> and have any complaint properly investigated<sup>219</sup>.
- Be treated with respect and courtesy<sup>220</sup>.
- Receive assistance to enable them to understand the procedure in relation to the complaint or receive advice on where to obtain assistance<sup>221</sup>.
- Have their complaint receive a timely and appropriate response<sup>222</sup>.
- Know the outcome of any investigation into their complaint<sup>223</sup>.
- Receive information about action taken in light of the outcome of a

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<sup>209</sup> s.13(6) The local authority Social Services and National Health Service Complaints (England) Regulations 2009

<sup>210</sup> s. 13(2) The local authority Social Services and National Health Service Complaints (England) Regulations 2009

<sup>211</sup> s.13(7) The local authority Social Services and National Health Service Complaints (England) Regulations 2009

<sup>212</sup> s.13(7) The local authority Social Services and National Health Service Complaints (England) Regulations 2009

<sup>213</sup> s.14(a) The local authority Social Services and National Health Service Complaints (England) Regulations 2009

<sup>214</sup> s.14(b) The local authority Social Services and National Health Service Complaints (England) Regulations 2009

<sup>215</sup> s. 14(3) The local authority Social Services and National Health Service Complaints (England) Regulations 2009

<sup>216</sup> s.14(4) The local authority Social Services and National Health Service Complaints (England) Regulations 2009

<sup>217</sup> s.14(2)(a) The local authority Social Services and National Health Service Complaints (England) Regulations 2009

<sup>218</sup> s.3(2)(a) The local authority Social Services and National Health Service Complaints (England) Regulations 2009

<sup>219</sup> s.3(2)(b) The local authority Social Services and National Health Service Complaints (England) Regulations 2009

<sup>220</sup> s.3(2)(c) The local authority Social Services and National Health Service Complaints (England) Regulations 2009

<sup>221</sup> s.3(2)(d) The local authority Social Services and National Health Service Complaints (England) Regulations 2009

<sup>222</sup> s.3(2)(e) The local authority Social Services and National Health Service Complaints (England) Regulations 2009

<sup>223</sup> s.3(2)(f) The local authority Social Services and National Health Service Complaints (England) Regulations 2009

complaint<sup>224</sup>.

- Take their complaint to the Parliamentary and Health Service Ombudsman; if they are not satisfied with the way their complaint has been dealt with by the PCT.
- Make an application for judicial review if they think they have been directly affected by an unlawful act or decision of an NHS body.
- Compensation where they have been harmed by negligent treatment.

## **8.11 Judicial review**

Judicial review is the procedure that enables someone to challenge a decision of a public body, such as the NHS organisation or the Secretary of State for Health on the basis that the decision is unlawful.

A decision may be unlawful if:

- The decision maker does not have the power to make the decision or is using the power improperly
- The decision is irrational
- The procedure followed by the decision maker was unfair or biased
- The decision was in breach of the Human Rights Act 1998
- The decision breaches EU law

Judicial review is not a form of appeal. The judge will look at the process of how the decision was made, rather than judging the decision itself. To be entitled to make a claim for judicial review someone must have a direct, personal interest in the action or decision being challenged.

The claim will be heard by the administrative court, although they are unable to review decisions of superior courts, such as the Court of Appeal.

The court can make the following orders: -

- A mandatory order (i.e. requiring the public body to do something)
- A prohibiting order (i.e. preventing the public body from doing something)
- A quashing order (i.e. quashing the public body's decision)
- A declaration
- Damages under the Human Rights Act 1998

It should be rare for matters concerning NHS continuing healthcare to be challenged via judicial review, as under National Framework and the NHS Continuing Healthcare (Responsibilities) Directions 2009, there are clear mechanisms for requesting a review of a decision for eligibility made by a PCT and PCTs and local authorities must have an agreed dispute resolution procedures.

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<sup>224</sup> s.3(2)(g) The local authority Social Services and National Health Service Complaints (England) Regulations 2009

An application for judicial review requires the permission of the court, at which point it will first consider whether the claimant has exhausted other mechanisms for resolving the dispute. Since the Coughlan and Grogan cases, there have been a limited number of cases brought to the court by way of judicial review.

### **St Helens Borough Council v Manchester PCT [2008] EWCA Civ 931**

St Helens Borough Council appealed against a decision that it was responsible to pay for the cost of care for a woman (PE), who had substantial care needs. Manchester PCT decided that her needs were not primarily health care.

PE was a woman in her mid-thirties who suffered from Dissociative Identity Disorder, more commonly called 'multiple personality disorder'. The annual cost of her care was in the region of £675,000. PE required three carers during the day and two during the night, to provide support with daily living, including taking medication, and in dealing with her aggressive and sometimes self-harming behaviour.

The grounds for judicial review in the permission hearing in the High Court ([2007] EWHC 2391 (Admin)) were:

- (i) that the views of the MDT were inaccurately recorded and communicated to the panel, and that they did not apply the applicable eligibility criteria;
- (ii) that the panel did not take all relevant material into account;
- (iii) that the panel misapplied the criteria;
- (iv) that the panel's approach to sharing funding responsibility misapplied their own criteria;
- (v) PE's condition was unique, complex and fluctuating, so the panel's conclusion was irrational as her condition could not be more serious, and that, if her needs were not health care needs, no one with mental disability would ever have such health care needs.

In refusing permission for judicial review the High Court judge did not consider that any error in the MDT's thinking and conclusion was shown to have carried through into the panel's decision. It would be extraordinary if the panel were obliged to read every report ever written about PE. It was for the panel itself to decide what should be taken into account. The sifting process used by the panel did not make its decision perverse. The panel members had stood back and considered the needs as a whole and gave individual criteria sufficient weight. Given the expertise of the panel the irrational challenge was not arguable. They included social care experts, mental health experts, nursing care experts, a consultant psychotherapist, and members who were not employed by the PCT and who were employed by a local social services authority.

The panel had considered that PE's care was unusual but not unique and that the

complexity in her care was the result of the breakdown of her relationship with the council rather than something intrinsic in her care needs. The panel's decision was consistent and reflected the overall recommendation of the MDT.

The council contended in its appeal, that this is a case where permission for judicial review should be granted as a case in which there are conflicting decisions of two public authorities, each exercising statutory powers, and that the court should decide for itself the substantive question whether PE's care needs are the responsibility of St Helens or the PCT. It did not contend that the eligibility criteria were unlawful.

Interestingly, the judge said the following in relation to his refusal to allow permission to challenge the PCT,

*'I had in mind here the idea that most of the care was in the nature of looking after, helping and on occasions restraining PE, not administering to or caring for her health; and that, although it was intense, sustained and perhaps complicated care, those features did not appear to convert what was essentially social care into health care'.*

The only ground of appeal granted by the court was whether the judge was correct to decide that the test to be applied to the challenge to the PCT's decision was an orthodox Wednesbury (unreasonable) test.

The court held:

1. The question of whether PE's needs were primarily health care needs was to be determined by a highly structured statutory process deriving from, but not exclusively referable to the National Health Service Act 2006, ss1-3. It was a decision to be taken with reference to guidance and directions. The structure included the agreement with the council of eligibility criteria, recommendations from a MDT on which there was social services expertise and membership. The PCT's panel then had to decide whether the individual's needs were primarily health care needs. The Secretary of State has a degree of judgment as to what health care services and facilities he considers necessary, reasonable and appropriate to provide as part of a comprehensive health care service. This judgment is delegated to the PCT whose decision was amenable to orthodox judicial review, but the substantive decision was, or was likely to be, intrinsically beyond the normal capacity of the court in judicial review proceedings.

Referring to the 2001 continuing NHS healthcare guidance, the judge noted that the eligibility criteria were based on 'the nature or complexity or intensity or unpredictability of health care needs'. It did not mean that care needs are health care needs, if they are by nature complex, intense or unpredictable, since they have to be health care needs in the first place, as they require regular supervision by a member of the NHS team.

2. The council did not have an equivalent or equivalently structured decision making process which could hold its own against those of the Secretary of State, through the PCT, under the NHS Act 2006.

3. The NHS Act 2006 was the dominant Act and the decision under it was the determinative decision as the National Assistance Act 1948 provided assistance as a last resort, so if a person's care needs were not primarily health care needs, they would be social services care needs. The decision is delegated by statute to the PCT and the council, albeit by the one primary decision maker - the Secretary of State. As such there was no head-on collision between two comparable decisions. It followed that a challenge to the PCT's decision would be by orthodox judicial review where the court was not required to determine the substance of two conflicting decisions.

It should be noted that the PCT following a fresh MDT recommendation agreed that PE's care needs were primarily health care needs.

**Jones v (1) Powys Local Health Board and (2) Neath Port Talbot Local Health Board (2008) EWHC 2562 (Admin)**

The High Court considered whether it was an abuse of process for a claim for the restitution of nursing home fees to be brought as a freestanding claim in the High Court, that would have involved a review of the detailed merits of the decision, rather than by way of a judicial review.

In Wales, as in England, a review mechanism had been established for dealing with retrospective claims for restitution of care costs. The claimant was dissatisfied with the outcome of this review process. The Judge said that he was far from persuaded that a civil action in the High Court was the optimum way of resolving such disputes, at least where the claimant has previously referred the matter for consideration to a specialist review body (which in contrast to the High Court) is experienced in the determination of the needs of a person for continuing healthcare.

Any such claims should not be brought by way of judicial review. It is a general principle that a claimant should have exhausted alternative forms of remedy through the review mechanism first before commencing judicial review proceedings. In this case the court made it clear that it was not ruling on cases where no attempt had been made to resolve disputed cases through the established review mechanism.

However the judgment indicates that the High Court felt that it was most appropriate for such cases to be dealt with by specialist review panels.

**R (on the application of Green) v South West SHA and Others (2008) EWHC 2576 (Admin)**

It was argued that when considering a claim for restitution the review panel had made its decision applying criteria that were unlawful and had consequently reached

a decision which was unlawful. However, the court admitted as evidence a witness statement from the chair of the review panel, which expanded (but did not depart from) the decision letter, explaining how the panel had interpreted and applied the criteria in this case.

On the basis of the evidence taken together the High Court found that there was no basis to conclude that the review panel unlawfully departed from the Primary Healthcare Needs Test when applying the eligibility criteria and consequently the claim for judicial review failed.

**R (on the application of Alyson Booker) v NHS Oldham [2010] EWHC 2593 (Admin)**

Ms Booker was aged 19 years and a ventilator dependent tetraplegic, as result of a road traffic accident. She had been assessed by the Primary Care Trust (NHS) as being eligible for NHS continuing healthcare and had been receiving her care as such. She subsequently reached a settlement for a personal injury award for her injuries to be paid to her from December 15, 2010.

The NHS planned to withdraw funding for her care from October 1, 2010, as she had no reasonable requirement for the provision of its services by reason of the damages she would receive, as she had elected to receive her continuing care on a private basis, pursuant to the Law Reform (Personal Injuries) Act 1948, s2(4) as explained by the Court of Appeal in *Eagle v. Chambers* [2004] EWCA Civ 1033.

Ms Booker had entered into undertakings designed to eliminate the possibility of a double recovery in the event that she continued to be cared for by the NHS after the 15 December 2010, and to facilitate the commencement of periodical payments from 15 December 2010 and the provision of care for her prior to that date in the event that such care was not provided by the NHS.

Ms Booker sought judicial review of the decision as she had been assessed as needing a certain level of future care, and it was unlawful for the NHS to withdraw that service before 15 December 2010.

The court held

1. The NHS decision to withdraw continuing care was unlawful and irrational. There is nothing within the National Framework document that supports the conclusion that the NHS was entitled to refuse continuing healthcare provision on the basis adopted, as eligibility is based on need. A claimant who was successful in recovering damages was entitled to do with the damages as he or she pleased. There was no clear distinction between a person who was independently wealthy or was insured in relation to medical expenses and someone who had sufficient means to provide for his or her care privately by reason of what had been recovered in damages (para 25).

To refuse treatment by reference to the patient's means would be contrary to the principle that the NHS was not a means-tested service (Section 1, para 2 of NHS Constitution and NHA Act 2006, s1 (3)) and was provided to patients on the basis of their medical needs, without reference to their financial position.

2. The principle that the tortfeasor pays applies to the assessment of damages in personal injury litigation (i.e. the claimant is entitled to have her loss made good, so far as this is possible, by the provision of accommodation and care) but it had no place in determining whether NHS care should be withheld. *Peters v East Midlands SHA* (2009) EWCA Civ 145, (2010) QB 48 applied (para.26).

In deciding whether a service was reasonably required or was necessary to meet a reasonable requirement, the NHS was bound to have regard to its target duty to promote a comprehensive health care service free at the point of delivery (s.1 (1) and s.1 (2) of the NHS Act 2006), the NHS constitution and the principle that access to NHS services was based on a person's clinical need and not their ability to pay and the National Framework document, which did not support the notion that a person should not be treated as eligible by reference to their ability to access funding for such care from another source (para.27).

3. There was no general policy not to provide such healthcare to someone otherwise eligible to receive it because they could have but have not claimed it from a tortfeasor. This was not a case where the NHS has decided that a particular form of treatment could not be provided because it is low on the list of priorities nor a case where the NHS has decided that it could not afford to provide care for everyone who is otherwise eligible to receive it because it does not have the funds to do so, and as such was distinguished from *R (on the application of Rogers) v Swindon NHS Primary Care Trust* (2006) EWCA Civ 392, (2006) 1 WLR 2649. The NHS had decided to refuse care because Ms Booker had the means of funding a privately provided care package. The NHS stance was neither rational nor lawful. Ms Booker's need for continuing healthcare would only be removed when a private package had been successfully established and implemented.

4. Nothing in the judgment should be taken to express or imply a view that the social and economic expediency of requiring a tortfeasor or his insurer to pay for the services that have been or will have to be provided by the NHS or other state funded bodies (*Crofton v NHS Litigation Authority* (2007) EWCA Civ 71, (2007) 1 WLR 923 considered). If the state is to be relieved of the cost of caring for the victims of torts then the remedy lies in primary legislation which permits that cost to be recovered by the NHS or its constituent bodies direct from the insurers of the tortfeasor concerned rather than by individual decision-making of the sort that has occurred in this case (para.31).

## **9 RETROSPECTIVE CLAIMS**

A retrospective claim is needed when a person has died before the NHS continuing healthcare assessment was undertaken or completed, or where a direct request from a person or a family member is received to review their needs, often in light of a change of circumstances. Most claims will involve an element of retrospective review, as payment is calculated from the date the decision of eligibility was made, yet the person's needs may have been the same for a period before the decision as made. Retrospective claims need to spell out the period the alleged eligibility covers.

### **9.1 Time limits for retrospective reviews**

#### ***Pre 1996***

Prior to April 1996, eligibility criteria for NHS continuing healthcare was drawn up locally, with minimal national guidance. However, as there was no obligation to have any written criteria, it is not possible to make retrospective claims for NHS continuing healthcare prior to this date.

In April 1995, the Department of Health issued national guidance for the first time to Health Authorities in England. This set out a broad framework containing only a list of issues that must be addressed. The Department of Health required each of the 95 Health Authorities (as they were at the time) to develop its own local criteria in accordance with the issues to be addressed for implementation from April 1996.

Subsequent guidance was issued in February 1996 advising against the use of over restrictive eligibility criteria. The guidance was all replaced following the Coughlan judgment.

#### ***1996-2004***

The Health Service Ombudsman published a report in February 2003 (NHS funding for long term care of older and disabled people) which investigated the way in which the former Health Authorities set and applied their criteria for the funding of NHS continuing healthcare.

Following the report, PCTs were asked to review decisions taken regarding NHS continuing healthcare from April 1996 to ensure they were Coughlan compliant. The reviews were to look at cases from 1<sup>st</sup> April 1996 to 1<sup>st</sup> April 2004 (or where the majority of the care was during that period and where payment was made towards that care). The time limit for those reviews ended on 30<sup>th</sup> November 2007, unless there were exceptional circumstances (as agreed between David Nicholson [the Chief Executive of NHS England] in conjunction with the PHSO). It is no longer possible to make retrospective claims for this period unless there are exceptional circumstances.

### ***2004-2007***

Where retrospective claims are made for this period, cases will be reviewed against the local eligibility criteria that were in place at that time rather than a National Framework.

Some matters will span a time frame that crosses the introduction of the National Framework in October 2007 and consequently require to be considered against two sets of criteria to ensure eligibility is determined against the correct criteria for that time.

A request is needed from the relevant PCT for copies of the local eligibility criteria in place at the relevant date to enable a comparison of the needs of the individual with the criteria to assess eligibility. It is important to check that the then eligibility criteria was Coughlan compliant.

## **9.2 Errors in past assessments**

If the person was assessed as not needing NHS continuing healthcare in the past using previous criteria, they can ask to be re-assessed against the National Framework. If they are re-assessed and are found to be eligible for they will not automatically be eligible for a reimbursement.

If the previous decision under the old system was properly taken, referring to lawful criteria appropriately applied and documented, then the person will not be entitled to a reimbursement. However, if the person's needs have not changed since the previous assessment under the old system, it should be considered whether the funding should be backdated to June 2007.

### ***Ruby Pearce- complaint against Torbay PCT, January 2007***

This case highlighted the issue of patients or their families being forced to sell their homes to fund care costs after being turned down for NHS continuing healthcare funding. Ruby Pearce, suffered from Alzheimer's disease and was unable to do anything for herself except chew and swallow. She was awarded NHS funded registered nursing care by Torbay PCT but not full NHS continuing health care funding. Her son, Mike Pearce had to sell the family home to pay for the cost of accommodating Ruby in a care home. Mike Pearce campaigned for five years to obtain funding for his mother, insisting that her primary need was for nursing care rather than social care. Eventually his case was reviewed by the Health Services Ombudsman, which recommended that Torbay PCT should pay £50,000 to Mike Pearce in retrospective care fees.

The Pearce case is notable as the recommendation to fund was based on draft guidelines for the National Framework which was not published until June 2007. At the time that Mike Pearce complained, Torbay PCT did not have up to date eligibility criteria in place, so it was decided to use the draft Framework's new Decision Support Tool.

### **9.3 How to make a retrospective application**

- (i) Read the criteria of the National Framework and DST (or the relevant criteria at the time and supporting assessment tools) closely to see whether the person may have been wrongly charged for care.
- (j) Ask for the person's care needs to be assessed or re-assessed under the National Framework by writing to the PCT.
- (k) If the PCT does not agree to review the case or their response is not satisfactory, request an independent review of the decision by the independent review panel – sending a copy of this letter to the SHA stating that you are not satisfied with the decision and that you want an Independent Review.

## 10 WHICH PCT PAYS

### 10.1 The general principles

The general principles for establishing which PCT (the responsible commissioner) should pay for NHS treatment and care of a patient are as follows: -

- Where the patient is registered with a GP practice, the responsible commissioner will be the PCT, which holds the contract with that GP practice.
- If a patient is not registered with a GP practice, the responsible commissioner will be the PCT in whose geographical area the patient is usually resident.
- If the patient is unable to give an address, the responsibility will be determined by the PCT in which he/she is present, which will usually be the PCT where the unit providing the treatment is located<sup>225</sup>.

### 10.2 Moving area

The NHS (Functions of Strategic Health Authorities and Primary Care Trusts and Administration Arrangements) (England) (Amendment) Regulations 2006 came into force on 1<sup>st</sup> April 2006 and introduced changes to the PCT responsible for the NHS contribution to packages of long-term care for adults with certain care needs who are placed in care homes or hospitals in the area of another PCT.

Where a PCT ('the placing PCT') arranges such a placement, whether on its own or jointly with another body (for example, a local authority), the placing PCT remains responsible for the NHS's contribution to the care, even where the person changes their GP practice (and associated PCT)<sup>226</sup>.

Where a patient is receiving NHS continuing healthcare in their own home and they decide to move home, the responsible commissioner is determined in accordance with their GP practice<sup>227</sup>.

The Department of Health 'Ordinary Residence: Guidance on the identification of the ordinary residence of people in need of community care services, England' states: -

*'If a care review determines that a person is no longer eligible for NHS continuing healthcare the duty for the provision of social care falls to the local authority in which the person is ordinarily resident under Part 3 of the National Assistance Act 1948<sup>228</sup>.'*

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<sup>225</sup> Regulation 3(7) of the National Health Service (Functions of Strategic Health Authorities and Primary Care Trusts and Administration Arrangements) (England) Regulations 2002 (S.I. 2002/2375) as amended by S.I. 2002/2548, 2003/1497, 2006/359 and 2007/559 ("the Functions Regulations")

<sup>226</sup> Paragraph 89 of Department for Health Guidance "Who Pays? Establishing the Responsible Commissioner"

<sup>227</sup> Paragraph 93 of Department for Health Guidance "Who Pays? Establishing the Responsible Commissioner"

<sup>228</sup> Paragraph 113 The Department of Health Ordinary Residence: Guidance on the identification of the ordinary residence of people in need of community care services, England

National Assistance Act 1948, s.24(6) sets out that prior ordinary residence is retained where a person is provided with NHS accommodation and this applies to people in receipt of accommodation as part of a package of NHS continuing healthcare. Therefore, where a person is placed in a care home in another local authority area for the purpose of receiving NHS continuing healthcare, they continue to be ordinarily resident in the local authority area in which they were ordinarily resident before entering the NHS accommodation<sup>229</sup>.

Where a person is accommodated in a care home as part of their package of NHS continuing healthcare and they cease to be eligible, but still need to remain in the care home, or be provided with accommodation elsewhere. Under National Assistance Act 1948, s.24 (6) the local authority in whose area the person was ordinarily resident immediately before being provided with NHS accommodation would be the authority responsible for funding the person's accommodation under Part 3 of the National Assistance Act 1948.

**Scenario: a person is discharged from NHS Continuing Healthcare**

Maureen is 72 years old. Three years ago, she suffered from a stroke which left her severely disabled with complex care need. She was assessed by her local PCT as needing NHS CHC and was moved from hospital to a rehabilitation unit within an independent sector care home in local authority B. This placement was fully funded by Maureen's local PCT. Before her stroke, Maureen had lived with her husband in local authority A.

A recent reassessment of Maureen's needs concludes that she is no longer eligible for NHS CHC and requires accommodation under Part 3 of the 1948 Act instead. The care home in which Maureen has been living offers her a place on a long-term basis and all those involved in her care agree that this arrangement best meets Maureen's needs.

Local authority B agrees to fund the placement on a "without prejudice" basis but immediately falls into dispute with local authority A over Maureen's place of ordinary residence. Local authority B contends that Maureen remains ordinarily resident in local authority A, where she has been living with her husband before her placement at the care home began. Local authority A argues that Maureen has acquired an ordinary residence in local authority B due to the length of time she has spent at the care home.

In this situation, when Maureen first enters the care home she is receiving NHS CHC, therefore the deeming provision in section 24(6) of the 1948 Act applies. This section provides that any person for whom NHS accommodation is provided is deemed to be ordinarily resident in the area in which they were ordinarily resident immediately before being admitted to hospital or other NHS accommodation. Therefore, whilst Maureen is receiving NHS CHC at the care home she remains ordinarily resident in local authority A, where she was living before her stroke.

Once Maureen's NHS CHC ceases and she is instead provided with Part 3 accommodation under the 1948 Act, the deeming provision in section 24(5) of the Act applies. This section sets out that any person provided with Part 3 accommodation shall be deemed to be ordinarily resident immediately before Part 3 accommodation was provided. Immediately before Maureen was provided with Part 3 accommodation she was living in the care home but was still ordinarily resident in local authority A due to the deeming provisions in section 24(6). Therefore, Maureen remains ordinarily resident in local authority A, as that was where she was ordinarily resident **immediately before** she began receiving Part 3 accommodation.

<sup>229</sup> Paragraph 114 The Department of Health Ordinary Residence: Guidance on the identification of the ordinary residence of people in need of community care services, England

### 10.3 Meaning of ‘ordinary residence’

There is no definition of ‘ordinary residence’ contained in the National Assistance Act 1948. The term should be given its ordinary and natural meaning<sup>230</sup>. The concept of ordinary residence involves questions of fact and degree. Factors such as time, intention and continuity have been taken into account<sup>231</sup>.

The courts have considered the meaning of ‘ordinary residence’. In *Shah v. London Borough of Barnet* (1983) 1 ALL ER 226. Lord Scarman stated,

*‘unless... it can be shown that the statutory framework or the legal context in which the words are used requires a different meaning I unhesitatingly subscribe to the view that “ordinary resident” refers to a man’s abode in a particular place or country which he has adopted voluntarily and for settled purposes as part of the regular order of his life for the time being, whether of short or long duration’*<sup>232</sup>.

Local authorities should always have regard to this case when determining the ordinary residence of people who have capacity to make their own decisions about where they wish to live. The starting presumption is that a person does have such capacity unless it is shown otherwise<sup>233</sup>.

Ordinary residence can be acquired as soon as a person moves to an area, if their move is voluntary and for settled purposes, irrespective of whether they own, or have an interest in a property in another local authority area. There is no minimum period in which a person has to be living in a particular place for them to be considered ordinarily resident there because it depends on the nature and quality of the connection with the new place<sup>234</sup>.

If the person lacks mental capacity to make the choice of where they live the *Shah* test does not apply. Instead it is determined by where the person usual home is based or considering the person’s physical presence, and the nature and purpose of that presence (*R v Waltham Forest LBC ex p Vale* [1985] 25<sup>th</sup> Feb, *The Times*). The *Vale* test is based on the assumption that the person lacking capacity cannot have adopted their place of residence voluntarily, as required by the *Shah* test<sup>235</sup>.

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<sup>230</sup> Paragraph 18 The Department of Health Ordinary Residence: Guidance on the identification of the ordinary residence of people in need of community care services, England

<sup>231</sup> Paragraph 19 The Department of Health Ordinary Residence: Guidance on the identification of the ordinary residence of people in need of community care services, England

<sup>232</sup> Paragraph 20 The Department of Health Ordinary Residence: Guidance on the identification of the ordinary residence of people in need of community care services, England

<sup>233</sup> Paragraph 21 The Department of Health Ordinary Residence: Guidance on the identification of the ordinary residence of people in need of community care services, England

<sup>234</sup> Paragraph 22 The Department of Health Ordinary Residence: Guidance on the identification of the ordinary residence of people in need of community care services, England

<sup>235</sup> Paragraph 30 The Department of Health Ordinary Residence: Guidance on the identification of the ordinary residence of people in need of community care services, England

In the Vale case it was held that a young person with severe learning disabilities was ordinarily resident at her parent's house where she was temporarily living at the time. It was stated that she was in the same position as a small child who was unable to choose where to live. It was held that where a person's learning disabilities were so severe as to render them totally dependent on a parent or guardian then 'the concept of her having an independent ordinary residence of her own which she has adopted voluntarily and or which she has a settled purpose does not arise' the possibility of the young person having an ordinary residence in a place that she had left or in a place where she may go in the future was rejected by the judge<sup>236</sup>.

The Vale test should **only** be used when making decisions about ordinary residence cases with similar material facts to those in Vale. If this test is not appropriate then the alternative approach set out in Vale should be used<sup>237</sup>.

The alternative approach involves considering a person's ordinary residence as if they had capacity. All the facts of the person's case should be considered, including physical presence in a particular place and the nature and purpose of that presence but without requiring the person themselves to have adopted the residence voluntarily<sup>238</sup>.

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<sup>236</sup> Paragraph 31 The Department of Health Ordinary Residence: Guidance on the identification of the ordinary residence of people in need of community care services, England

<sup>237</sup> Paragraph 33 The Department of Health Ordinary Residence: Guidance on the identification of the ordinary residence of people in need of community care services, England

<sup>238</sup> Paragraph 34 The Department of Health Ordinary Residence: Guidance on the identification of the ordinary residence of people in need of community care services, England

## **11. EFFECT OF ENTITLEMENT ON STATE BENEFITS**

### ***Future entitlement***

If the person was self-funding their care in a care home, or moving into a care home and they are receiving Attendance Allowance or Disability Living Allowance they should notify the Disability Benefits and Attendance Allowance helpline (08457 123456) of their entitlement to NHS continuing healthcare.

Any benefit will cease on the 29<sup>th</sup> day after the PCT begins to fund care or sooner if they have recently been in hospital.

If the person is living at home with the support of a NHS continuing healthcare package they can continue to receive Attendance Allowance or Disability Living Allowance.

The person will lose the severe disability element of Pension Credit when they are no longer entitled to Attendance Allowance or Disability Living Allowance.

State Pension is not affected by eligibility for NHS continuing healthcare.

### ***Past entitlement***

If the person successfully argues and obtains retrospective funding, they do not have to pay back state benefits they received, had they been found to be eligible at that time. However the benefits will be taken into account in the amount of interest the PCT pay the person.

### ***Calculation of interest***

The Parliamentary and Health Service Ombudsman's report, 'Retrospective Continuing Care Funding and Redress' published in March 2007, found maladministration against Greenwich PCT, which had relied on Department of Health's guidance. It had advised the NHS to pay recompense based on the principle of restitution for only those monies paid out in care fees. Their approach discouraged PCTs from considering full redress, including, for example, inconvenience and distress that individuals had suffered in making unnecessary difficult decisions about how to fund care. In response, the Department issued 'Government Guidance on Interest and Compensation in respect of Retrospective Payments'.

Interest should be paid on retrospective payments based on either using

- (i) The Retail Price Index formula without deductions for benefits received
- (ii) County Court judgment debt (in general, only County Court judgements for the payment of £5000 or more carry interest (Civil Procedure Rules 1998, 40.8.1), deducting benefits received. on various benefits.

## 12 INHERITANCE TAX POSITION

HM Revenue & Customs have confirmed that the following discounts apply to the value of funds received in respect of NHS continuing healthcare, which must be included in IHT forms:

Date of death prior to 16 <sup>th</sup> July 1999	100%
17 <sup>th</sup> July 1999 to 13 <sup>th</sup> February 2003	75%
14 <sup>th</sup> February 2003 to 16 <sup>th</sup> December 2004	40%
After 16 <sup>th</sup> December 2004	10%

Interest in respect of late payment of Inheritance Tax payments in respect of these cases must still be paid.

If a claim is underway when someone dies and has reached the point where an offer has been made by the PCT it is reasonable to expect executors to include that amount (with the appropriate discount) in the IHT 400. If the claim has not been quantified, or is not known about at the date of death, then details of the amount eventually paid should be reported in due course.

It is important to have regard to such a claim in considering whether the estate qualifies as an excepted estate.

### 13. NHS FUNDED NURSING CARE

Funding is provided by the PCT to care homes providing nursing care, to support the provision of nursing care by a registered nurse for those assessed as eligible<sup>239</sup>. The funding does not include the cost of non-nursing care or accommodation provided<sup>240</sup>. Consideration of eligibility for NHS funded nursing care is not an alternative to discussions about the appropriate level of fees payable to care homes for accommodation and other non-nursing services<sup>241</sup>. Accommodation and personal care costs are met by the local authority and/or the person based on the outcome of means testing<sup>242</sup>.

If an individual does not qualify for NHS continuing healthcare, the need for care from a registered nurse must be assessed. If it is determined that the individual's overall needs would be appropriately met in a care home providing nursing care this automatically leads to eligibility for NHS funded nursing care<sup>243</sup>.

Once the need for such care is agreed, the PCT is responsible for paying a flat rate contribution towards registered nursing care costs<sup>244</sup>.

The registered nurse input is defined in the following terms:

*'Services provided by a registered nurse and involving either the provision of care or the planning, supervision or delegation of the provision of care, other than any service which, having regard to their nature and the circumstances in which they are provided, do not need to be provided by a registered nurse.'*<sup>245</sup>

This does not include time spent by non-nursing staff such as care assistants (although it does cover the nurse's time monitoring or supervising care delegated to others)<sup>246</sup>.

#### 13.1 Principles

All individuals should be considered for NHS continuing healthcare before being considered for NHS funded nursing care<sup>247</sup>.

This should mean that the person would have an assessment, which would provide sufficient information to gauge the need for nursing care in residential accommodation without the need for further assessment. However, if the person

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<sup>239</sup> Paragraph 4 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>240</sup> Paragraph 6 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>241</sup> Paragraph 7 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>242</sup> Paragraph 11 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>243</sup> Paragraph 4 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>244</sup> Paragraph 4 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>245</sup> Paragraph 5 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>246</sup> Paragraph 6 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>247</sup> Paragraph 8 NHS funded Nursing Care Practice Guide (revised) 2009

was not eligible for NHS continuing healthcare, at the checklist stage they may require an appropriate assessment, such as Single Assessment Process or Common Assessment Framework to ensure all their needs are identified and that decisions reached are proportionate, reasoned and recorded<sup>248</sup>.

This process should always take place before a client enters a care home on a long-term basis (unless they are admitted in an emergency)<sup>249</sup>.

The single band of NHS funded nursing care was introduced on 1<sup>st</sup> October 2007 and replaced the previous low, medium and high bands of nursing care, which operated from 1<sup>st</sup> October 2001 to 30<sup>th</sup> September 2007. Since this date all eligible persons have been placed on the single band<sup>250</sup>.

### ***Position of those in a nursing home on the high band at 1.10.07***

People who were in receipt of the high band of NHS funded nursing care under the now superseded three-band system continue to be entitled to remain on this band until:

- (i) On review, it is determined that they no longer have any need for nursing care.
- (ii) It is determined their needs have changed, so that they would have moved into medium or low bands (that is their nursing care needs are now stable and predictable or nursing needs are low), in which case the person will be eligible to the flat band of contribution.
- c) They are no longer resident in a care home that provides nursing care.
- d) They become eligible for NHS continuing healthcare; or
- e) They die.<sup>251</sup>

Where (ii) above applies, the PCT must ensure all parties concerned are aware of the proposed change; the PCT should give at least 14 days notice of the change to both the resident and the care home<sup>252</sup>.

## **13.2 Assessments and decisions**

A registered nurse, employed by the NHS, should undertake the assessment working in partnership with the local authority to ensure that the client's health and social care needs can be identified and met appropriately by each organisation<sup>253</sup>. The nurse should identify and document the registered nursing needs and inform the resident and the PCT of that decision<sup>254</sup>. The nurse should be familiar with recognised models of nursing, have experience relevant to the needs of the

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<sup>248</sup> Paragraph 8 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>249</sup> Paragraph 9 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>250</sup> Paragraph 11 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>251</sup> Paragraph 12 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>252</sup> Paragraph 12 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>253</sup> Paragraph 13 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>254</sup> Paragraph 14 NHS funded Nursing Care Practice Guide (revised) 2009

individual, and be familiar with the care domains of the DST<sup>255</sup>. The nurse is personally and professionally accountable for his or her own practice. This means that the nurse is answerable for their actions and omissions regardless of advice or directions from another professional<sup>256</sup>.

PCTs should be clear that a decision about the need for NHS funded nursing care should only be made after a decision about eligibility for NHS continuing healthcare<sup>257</sup>.

The process of assessment and decision-making should be person centred. This means the resident (or prospective resident), their perception of their needs and their preferred models of support are at the heart of the assessment and the care-planning process.<sup>258</sup> This should be documented and taken into account, along with the risks of different types of provision and fairness of access to resources<sup>259</sup>. (See Annex C of the NHS Funded Nursing Care Practice Guide (revised) 2009 for the assessment documentation).

The assessment can take place in a hospital or non-hospital setting but it should be considered that the assessment which takes place in a hospital setting may not always reflect the person's capacity to maximise their potential and they may recover further<sup>260</sup>.

The assessor should take this into consideration together with whether that provision of further NHS funded services might be appropriate. This may include: -

- Therapy and /or rehab
- Repaid response support
- Hospital at home
- Supported discharge
- Intermediate care; or
- And interim package of support in the client's own home or in a care home<sup>261</sup>.

The assessor should also consider whether the assessment should be deferred until an accurate assessment can be made. However, there must be no gap in the provision of appropriate support to meet the individual's needs<sup>262</sup>.

The assessment of registered nursing needs should help the person, their carer/representative understand the extent and nature of the nursing care required to

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<sup>255</sup> Paragraph 15 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>256</sup> Paragraph 16 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>257</sup> Paragraph 20 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>258</sup> Paragraph 26 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>259</sup> Paragraph 26 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>260</sup> Paragraph 22 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>261</sup> Paragraph 23 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>262</sup> Paragraph 24 NHS funded Nursing Care Practice Guide (revised) 2009

meet their care needs and find the most appropriate environment in which to meet those needs<sup>263</sup>.

The decision about whether support should be provided in the form of a care home with nursing should take into account all the person's nursing and other needs based on what is known about the client's condition and their usual behaviour over the course of a week, or a number of weeks<sup>264</sup>.

The nurse should also consider the potential outcomes if support were not to be provided, or was provided in different ways. In making their evaluation, the registered nurse should also focus on the individual's preferences, the impact of any decisions on the individual's independence, and risks involved for the individual, their family and others close to them<sup>265</sup>.

A care plan should be developed, clearly setting out how the person's needs entail 'the provision of care or the planning, supervision or delegation of the provision of care' by a registered nurse<sup>266</sup>. This includes not only direct input from a nurse but also time spent in the planning, supervising and monitoring of care delivered by someone else, who may or may not be a nurse<sup>267</sup>.

The care plan should identify the need for care (or supervision of care) by a nurse across the same comprehensive care domains as those used in a DST (which may already be recorded)<sup>268</sup>.

Using all available evidence, and their professional skill and judgment, the nurse should record the level and quantity of nursing need and any specific risk factors against each care domain. A recommendation on the nature of the nursing care needed should be made in each relevant domain and the rationale for that recommendation<sup>269</sup>.

If the decision about registered nursing care is being reached subsequent to a full assessment of eligibility for NHS Continuing Healthcare, there is a space in the DST to record the outcome of that process<sup>270</sup>.

Only the needs of the individual should be recorded, and this should not be influenced by the restrictions placed on the delivery of care by the hospital or care home environment<sup>271</sup>.

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<sup>263</sup> Paragraph 28 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>264</sup> Paragraph 33 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>265</sup> Paragraph 33 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>266</sup> Paragraph 34 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>267</sup> Paragraph 34 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>268</sup> Paragraph 34 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>269</sup> Paragraph 35 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>270</sup> Paragraph 36 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>271</sup> Paragraph 37 NHS funded Nursing Care Practice Guide (revised) 2009

The nurse involved in this decision should consider the following:

- Does the person have registered nursing needs that can be met in their own home by community nursing services?
- Does the person have registered nursing needs of a type or level where they require a care home providing a nursing care environment?
- Do they want to/need to be in a residential setting or is another option preferred or more appropriate?<sup>272</sup>

Once it is agreed with the person and/or their carer that a care home offers the best environment in which their needs can be met, the next phase is to set goals within the care plan. This process should usually be completed before a long-term admission to a care home takes place and should be used to inform the identification of an appropriate care home<sup>273</sup>.

When a local authority is involved, the relevant professionals should be working closely together to identify the care required which will inform the selection of a care home able to meet those needs<sup>274</sup>.

The individual, their carer and/or representative are responsible for making the choice of care home supported and advised by the relevant professionals. Where a local authority is funding some or all of the non-nursing care needs they will advise on funding or other factors that will need to be taken into account in making this choice<sup>275</sup>.

### 13.3 Care plans

A care plan should set out the services expected to be provided by the care home and by the NHS<sup>276</sup>. The care plan should also set out other services that have been identified and agreed to be provided by the local authority and/or the NHS. The person should not have to pay for any services included in the care plan<sup>277</sup>.

The local authority is responsible for assisting a self-funded person in arranging a care home placement where the individual is unable to do this themselves and has no relative or friend willing and able to do this for them<sup>278</sup>.

PCTs should ensure that their contracting arrangements with care homes that provide nursing care give clarity on the responsibilities of nurses within the care home and of community nursing services. No gap in service provision should arise

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<sup>272</sup> Paragraph 38 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>273</sup> Paragraph 39 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>274</sup> Paragraph 40 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>275</sup> Paragraph 40 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>276</sup> Paragraph 41 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>277</sup> Paragraph 41 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>278</sup> Paragraph 41 NHS funded Nursing Care Practice Guide (revised) 2009

between the two sectors<sup>279</sup>.

### **13.4 Equipment**

If the person requires equipment to meet their care needs, there are several routes by which this may be provided:

- (a) The care home may be required to provide certain equipment as part of regulatory standards or as part of their contract with the PCT. (For more detail see the Care Quality Commission's website at [www.cqc.org.uk](http://www.cqc.org.uk))
- (b) People who are entitled to NHS funded nursing care have an entitlement to joint equipment services and the PCT/local authority should ensure availability is taken into account in the planning and funding arrangements.
- (c) If the person requires equipment to meet specific assessed needs identified in their care plan which are not available through (a) or (b) above, the PCT and/or the local authority should make the appropriate arrangements to meet these needs<sup>280</sup>.

### **13.5 Monitoring and review of needs**

Reviews play a critical role in ensuring that the nursing needs of the individual are being appropriately met and provides an opportunity to review the goals set in the care plan<sup>281</sup>. A case review should be undertaken no later than 3 months after the initial eligibility decision, in order to re-assess care needs and to ensure that those needs are being met<sup>282</sup>. Reviews should then take place annually, as a minimum although some cases will require more frequent reviews<sup>283</sup>.

They should consider whether the person's level of independence has improved to the point where permanent admission to a care home providing nursing is no longer appropriate and if so, what other forms of care should be considered<sup>284</sup>. The local authority, if responsible for any part of the care, will have a requirement to review needs<sup>285</sup>.

Eligibility for NHS continuing healthcare must also be considered at reviews<sup>286</sup>. Dispute resolution follows the same process as for NHS continuing healthcare<sup>287</sup>.

### **13.6 Short term stays**

When the person goes into care for a short period of time; of less than six weeks,

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<sup>279</sup> Paragraph 42 NHS funded Nursing Care Practice Guide (revised) 200

<sup>280</sup> Paragraph 49 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>281</sup> Paragraph 52 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>282</sup> Paragraph 52 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>283</sup> Paragraph 54 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>284</sup> Paragraph 52 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>285</sup> Paragraph 55 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>286</sup> Paragraph 53 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>287</sup> Paragraph 56 NHS funded Nursing Care Practice Guide (revised) 2009

such as:

- in an emergency or crisis;
- whilst awaiting completion of a nursing determination
- for a trial period
- for respite care<sup>288</sup>

they will qualify for NHS funding without the need for assessment (if it is known at the outset that the stay will be less than 6 weeks)<sup>289</sup>.

If there are a series of planned respite care stays in a care home that is likely to exceed six weeks in any 12 month period, an assessment should be carried out at the outset unless the person is already receiving NHS continuing healthcare<sup>290</sup>.

### **13.7 Hospital admissions**

When a person is admitted to hospital, payments for the NHS funded nursing care should be stopped until they return to the care home. This should be reflected in local NHS contracts<sup>291</sup>. Local authorities and individuals will need to agree separately with care homes the level of fees necessary to secure the place in the care home in the event of such temporary absences<sup>292</sup>.

In order to secure the place in a care home and to avoid people being asked to pay any shortfall, PCTs will consider the payment of an equivalent sum as a retainer<sup>293</sup>.

When the person has been placed in residential care under an local authority contract, the local authority will usually continue to pay the care home the full fee for a set period (usually 6 weeks), followed by a reduced payment thereafter<sup>294</sup>.

### **13.8 Death of a care home resident**

Local authorities will often pay a full fee for a certain period of time following death. PCTs will often agree a similar payment in these circumstances<sup>295</sup>.

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<sup>288</sup> Paragraph 62 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>289</sup> Paragraph 63 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>290</sup> Paragraph 64 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>291</sup> Paragraph 69 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>292</sup> Paragraph 69 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>293</sup> Paragraph 70 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>294</sup> Paragraph 70 NHS funded Nursing Care Practice Guide (revised) 2009

<sup>295</sup> Paragraph 73 NHS funded Nursing Care Practice Guide (revised) 2009

## **14 WHAT SHOULD HAPPEN BEFORE DISCHARGE FROM HOSPITAL**

### **14.1 Rehabilitation**

The person should be offered rehabilitation if their needs meet the NHS's eligibility criteria and the consultant feels this is the most appropriate action. This can include physiotherapy to improve mobility and occupational therapy to manage the risks involved in daily activities amongst other things. However this may mean a longer stay in hospital or in other accommodation such as a rehabilitation unit.

The extent of available services across the country varies but the NHS should pay for any rehabilitation offered.

### **14.2 Assessments**

All PCTs, NHS trusts and social services must follow the Single Assessment Process for older people (SAP) when they carry out any assessment of needs, which will look at their social, emotional, spiritual, cultural and psychological needs as well as any housing, financial, physical and mental health needs. If, following a SAP, it appears that person needs help and support they should be supported by a social worker or care manager. The result of the assessment should be recorded on a written care plan and the person should be given a copy.

There are a number of different assessments that may take place in hospital: -

- (i) Contact: If needs have not changed much during the person's stay in hospital, a meeting will be held during which any potential difficulties can be discussed.
- (ii) Overview: Examines different areas of the person's life such as personal care and physical well being to establish any need for support in these areas.
- (iii) Specialist: If during the assessment, it transpires that further examination by a suitably trained professional to establish identified risks is required.
- (iv) Comprehensive: This is the resultant assessment which will put together all the assessments that have taken place

The person and their family are entitled to receive written information about the assessment. This information includes

- Information about NHS continuing healthcare and NHS funded nursing care
- Combined package of health and social care at home
- Services you can expect from the PCT or NHS Trust

- Services you can expect from the local authority social services department– including details of costs
- The complaints procedure
- If the person has nowhere to live or there are problems with housing needs, then a representative from housing services should also be involved in the assessment

### **14.3 Discharge**

Every hospital must have its own discharge policy, in accordance with the Department of Health's 'Discharge from hospital: pathway, process and practice' best practice guidance (Published January 2003).

The patient should not be discharged until they are medically fit. The hospital must inform the patient in advance of date of discharge and must make sure they have transport home and that any required medication is prepared. They must not be discharged until the services/equipment they need has been arranged and is in place. A full and appropriate care package should be arranged in time for the patient's discharge to avoid the person remaining in an acute hospital bed for longer than necessary.

The discharge process should include

- An assessment of the patient's needs, living environment and support networks
- The patient's needs should be established and recorded on a care plan
- Assessment of the patient's ability to pay for services
- Ensuring all required services are in place ready for discharge
- Monitoring and adjustment of the care plan to ensure ongoing needs are met

### **14.4 The Community Care (Delayed Discharges etc) Act 2003**

The Community Care (Delayed Discharges etc) Act 2003 (the Act) places a duty on the NHS and local authority social services department to work together to ensure safe discharges are co-ordinated in a timely manner to prevent older people remaining in hospital unnecessarily.

The Act only applies if the patient has received acute hospital care, which is defined as:

*'Intensive medical treatment provided by or under the supervision of a consultant, which is for a limited time after which the patient no longer benefits from that treatment'*

The Act outlines the duty of the NHS to tell the local authority social services which has responsibility for the patient, when a patient is ready for discharge. The local

authority then has a limited period of time in which to undertake an assessment and put in place services to ensure that a person can be discharged safely.

In the event that the local authority fail to undertake the assessment or put in place the services, they are fined by the NHS for each day the patient remains in hospital, when they are ready for discharge. If any part of the delay relates to the health services or family responsibility then the local authority will not be fined.

This Act should not be used to make the patient feel pressurised into accepting premature discharge. If the patient feels that appropriate care has not been arranged then this should be raised with the ward staff before formal discharge.

### **14.5 Intermediate/Reablement Care**

Intermediate care services<sup>296</sup> sometimes called ‘reablement services’, covers a range of services designed to assist people to remain independent, regain their independence to enable them to return home or to prevent them from returning to hospital unnecessarily. They can be provided by the NHS or local authority in the person’s own home or in a care setting (care home/day hospital) for usually a maximum of 6 weeks. Intermediate care must be provided free of charge by the NHS.

If the hospital consultant decides the person meets the criteria for intermediate care the local authority will be responsible for assessing the person’s needs.

### **14.6 Palliative care**

The NHS has responsibility to provide care fees for people in the final stages of a terminal illness. This can be provided in a hospital, hospice, care home or in the person’s own home. People who require palliative care, as they are in the final stages of a terminal illness, must be ‘fast-tracked’ for immediate provision of NHS continuing healthcare. In the community, this is provided by social care professionals and is designed to ensure that the person is kept as comfortable and has the best quality of life possible.

### **14.7 Moving back home with risk**

Hospital staff and social services should explore possible options available including care at home and providing equipment or an adaptation to the person’s home. Any equipment provided in the person’s home such as grab rails/commodore which cost less than £1,000 must be provided free of charge<sup>297</sup>. These are accessed via an assessment by an occupational therapist.

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<sup>296</sup> The 2009 Guidance can be found at:

[www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_103146](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_103146)

<sup>297</sup> The Community Care (Delayed Discharges etc) Act (Qualifying Services) (England) Regulations 2003 (SI 2003/1196)

If the person decides to return home against the advice of professionals they can do so, but they may be asked to sign a disclaimer accepting the risk.

The local authority can take into account their own resources when deciding how the person's needs will be met, not whether to meet an eligible need<sup>298</sup>. Services commissioned by the local authority as a community care service are subject to a means test<sup>299</sup>. Charges made for services should not reduce the person's income to below 'basic' levels of Income Support, or Guarantee Credit of Pension Credit plus a buffer of not less than 25%, to safeguard the user's independence.

They may agree to provide services up to the same level of cost of their standard rate of care home fees providing the person is not at unacceptable risk, but cannot operate inflexible price ceilings, to cater for exceptional circumstances.

The person cannot be forced into a care home against their will, although there are exceptions, such as those who are eligible for detention under the Mental Health Act 1983, or lack mental capacity and are subject to a Court of Protection order or safeguard authorisation for their deprivation of the liberty in a care home and/or move into a care home.

#### **14.8 Reviews of care packages**

Any care package arranged while the person is in hospital should be reviewed within two weeks of discharge to confirm that the package is meeting their needs. This can either be by a meeting or telephone call from the social worker.

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<sup>298</sup> Khana v Southwark LBC [2002] LGR 15

<sup>299</sup> LAC (2001) 32, updated in November 2003, sets out mandatory guidance on charging for domiciliary care

## 15 AFTER CARE SERVICES UNDER THE MENTAL HEALTH ACT 1983

Section 117 of the Mental Health Act 1983, states that PCTs and local authorities have a joint duty to provide after care services to individuals who have been detained under section 3 for treatment, or admitted to a hospital in pursuance of a hospital order made under section 37, or transferred to a hospital in pursuance of a hospital direction made under section 45A or a transfer direction made under section 47 or 48, and then cease to be detained and (whether or not immediately after so ceasing) leave hospital, until such time as they are satisfied that the person is no longer in need of such services.<sup>300</sup> As such responsibilities for the provision of s117 lies jointly with local authorities and the NHS.<sup>301</sup> Local authorities and PCTs should have agreements in place detailing how they will carry out their s.117 responsibilities, and these agreements should clarify which services fall under s.117 and which authority should fund them<sup>302</sup>.

Aftercare services is not defined in the Act, however they would normally include social work, support in helping the ex-patient with problems of employment, accommodation or family relationships, the provision of domiciliary services and the use of day centre and residential facilities<sup>303</sup>.

There is no power to charge for services provided under s117 regardless of whether they are provided by the PCT or the local authority. It is therefore not necessary to assess eligibility for NHS continuing healthcare where all services in question are to be provided as after care services under s117<sup>304</sup>.

Only needs that are not after care needs should be considered for NHS continuing healthcare eligibility in the usual way, for example, the individual might develop physical health needs which are distinct from s.117 needs, and which separately constitute a primary health need<sup>305</sup> and it may be necessary to carry out an assessment for NHS continuing healthcare.<sup>306</sup>

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<sup>300</sup> Paragraph 113 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>301</sup> Paragraph 114 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>302</sup> Paragraph 4.13 NHS Continuing Healthcare Practice Guide March 2010

<sup>303</sup> *Clunis v Camden and Islington Health Authority* [1998] QB 978, 992 Beldam LJ

<sup>304</sup> Paragraph 115 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care; *R v Redcar & Cleveland BC ex parte Armstrong; R v Manchester City Council ex parte Stennett R; Harrow London BC ex parte Cobham*. House of Lords 25.7.02

<sup>305</sup> Paragraph 4.13 NHS Continuing Healthcare Practice Guide March 2010

<sup>306</sup> Paragraph 116 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

## 16 CHILD TO ADULT SERVICES

The term ‘continuing care’ has a different meaning in child and adult services<sup>307</sup>. There is a separate National Framework for NHS continuing health care in relation to children. For those who are moving from child to adult services, it is best practice that future entitlement to adult NHS continuing care to be clarified as early as possible<sup>308</sup>.

Children’s NHS continuing healthcare teams should notify whichever PCT will have responsibility for the child as an adult as soon as the young person reaches aged 14<sup>309</sup>. This should be followed up by a formal referral for screening at aged 16 to the adult NHS continuing healthcare team<sup>310</sup>.

At aged 17, eligibility for adult NHS continuing healthcare should be determined in principle by the relevant PCT so that effective packages of care can be commissioned in time for the individual’s 18<sup>th</sup> birthday<sup>311</sup>.

The decision on eligibility should be made using the relevant PCT’s usual adult NHS Continuing Healthcare decision-making process<sup>312</sup>.

If a young person who receives children’s NHS continuing health care has been determined by the relevant PCT not to be eligible for adult NHS continuing healthcare when they reach the age of 18 they should be advised of their non-eligibility and of their right to request an independent review, on the same basis as a NHS continuing healthcare decision regarding adults<sup>313</sup>.

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<sup>307</sup> Paragraph 119 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>308</sup> Paragraph 122 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>309</sup> Paragraph 123 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>310</sup> Paragraph 124 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>311</sup> Paragraph 125 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>312</sup> Paragraph 126 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>313</sup> Paragraph 127 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

## **17 CONSENT AND ACCESS TO HEALTH RECORDS**

### **17.1 Consent when the person has mental capacity**

When consent is requested to consider eligibility for NHS continuing healthcare. It should also include consent to obtain relevant health and social care records necessary to inform determination of eligibility and also consent for these to be shared with those involved in the eligibility process.

The person must also be aware of the range of records that may be required to reach an informed conclusion on eligibility which could include those from GP's, hospitals, community health services, local authority social care, care homes and domiciliary care/support services.

It is preferable that consent be recorded in writing where the person is not physically able to provide written consent they can give consent through verbal or other means<sup>314</sup>.

### **17.2 Consent when the person lacks mental capacity**

If there is concern that a person may not have the capacity to give consent to an assessment this should be determined in accordance with the Mental Capacity Act 2005 and the associated code of practice<sup>315</sup>.

A third party cannot give or refuse consent for an assessment for eligibility for NHS continuing healthcare on behalf of a person who lacks mental capacity, unless they have a valid and applicable Health and Welfare LPA or they have been appointed a Welfare Deputy by the Court of Protection<sup>316</sup>.

Where consent cannot be obtained the assessor should consider whether it is in the person's best interest for an assessment to be conducted. The assessor is protected from any liability in conducting the assessment without express consent, provided they are satisfied the person to be assessed lacks mental capacity to consent and it is in their best interest to be assessed.<sup>317</sup>

In such cases, the assessor must consult with any relevant third party who has a genuine interest in the person's welfare. This will normally include family and friends. The outcome of any 'best interest' decisions should be recorded<sup>318</sup>.

In this respect, if a person is acting under a registered enduring power of attorney, a property and affairs lasting power of attorney or as a deputy, they must act in the best interests of the incapacitated person by ensuring that they are properly assessed and therefore they will need to be consulted and can make a request for an

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<sup>314</sup> Paragraph 2.3.4 The NHS Continuing Healthcare Practice Guide March 2010

<sup>315</sup> Paragraph 39 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>316</sup> Paragraph 41 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

<sup>317</sup> Mental Capacity Act 2005, s5

<sup>318</sup> Paragraph 42 The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

assessment which assessment should not be refused.

### **17.3 Person centred approach to assessment and provision<sup>319</sup>**

There are many elements to a person centred approach to assessment and provision of care, but as a minimum it is necessary to: -

- Ensure that the person concerned is fully and directly involved in the assessment and the decision making process.
- Take full account of the individual's own views and wishes, ensuring that their perspective is clearly the starting point of every part of the assessment process.
  - The individual's own view of their needs and their preference as to how they should be met should be documented at each stage. They should be given as much choice as possible, particularly in the care planning process.
  - Where mental capacity issues impact on an individual's ability to express their views family members and others who know the individual well should be used to find out as much as possible on what the individual would want if they were able to express a view.
  - Where issues arise from needs and risks that may affect the care/support options available, these should be fully discussed with the individual<sup>320</sup>.
- The PCTs should consider this communication need and make appropriate arrangements.
  - It is important to assess whether the individual has any communication needs and if so, how these can be addressed, for example with an interpreter, use of simplified language or pictures.
  - Preferred methods of communication should be checked with the person or their representatives in advance.
  - If the communication need means that it takes the person longer to express himself or herself this should be planned in to the time allowed to carry out the assessment<sup>321</sup>.
- Obtain consent to assessment and sharing of records (where the individual has mental capacity to give this)
- Deal openly with issues of risk.
- Keep the individual informed.

The approach to carrying out assessments is of equal importance to the technical arrangements that are put in place. Many people will find it easier to explain their view of their needs and preferred outcomes if the assessment is carried out as a conversation, rather than working through an assessment document in linear fashion. It is important that the person's own view of their needs is treated equally alongside professional views<sup>322</sup>.

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<sup>319</sup> Paragraph 2.3 The NHS Continuing Healthcare Practice Guide March 2010

<sup>320</sup> Paragraph 2.3.2 The NHS Continuing Healthcare Practice Guide March 2010

<sup>321</sup> Paragraph 2.3.3 The NHS Continuing Healthcare Practice Guide March 2010

<sup>322</sup> Paragraph 2.3.3 The NHS Continuing Healthcare Practice Guide March 2010

## 17.4 Keeping the client informed

The person should be kept informed through the assessment process including:-

- Explaining timescales and key milestones
- Making the person aware of the other individuals involved
- Informing them of potential delays
- Providing a key contact person and ensuring a clear channel of communication between them and the MDT
- Helping the person to understand the eligibility process, as it progresses
- Keeping family members appropriately informed<sup>323</sup>.

## 17.5 Statutory rights to access records

There are two pieces of legislation that give a statutory right to access health records. The Data Protection Act 1998 (DPA) and The Access to Health Records Act 1990 (AHRA). The legislation that is relied upon will depend on whether person (or their representative, such as solicitor) is acting directly or whether a person's personal representatives are acting.

The Department of Health has produced its own guidance in relation to medical records called 'Guidance for Access to Health Records' (February 2010).

### *The Data Protection Act (DPA)*

The DPA defines a health record as

*'A record consisting of information about the physical or mental health or condition of an identifiable individual made by or on behalf of an health professional in connection with the case of that individual'.<sup>324</sup>*

A health professional is defined as,

- A registered medical practitioner, which includes any person who is provisionally registered under section 15 or 21 of the Medical Act 1983 and is engaged in such employment as is mentioned in subsection (3) of that section.
- A registered dentist as defined by section 53(1) of the Dentists Act 1984,
- A registered dispensing optician or a registered optometrist within the meaning of the Opticians Act 1989,
- A registered pharmacist or registered pharmacy technician within the meaning of the Pharmacists and Pharmacy Technicians Order 2007] or a registered person as defined by Article 2(2) of the Pharmacy (Northern Ireland) Order 1976,

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<sup>323</sup> Paragraph 2.3.6 The NHS Continuing Healthcare Practice Guide March 2010

<sup>324</sup> Paragraph 68(2) Data Protection Act 1998

- a registered nurse or midwife
- A registered osteopath as defined by section 41 of the Osteopaths Act 1993,
- A registered chiropractor as defined by section 43 of the Chiropractors Act 1994,
- Any person who is registered as a member of a profession to which [the Health Professions Order 2001] for the time being extends,
- A child psychotherapist,
- A scientist employed by such a body as head of a department.

A 'health service body' means

- A Strategic Health Authority established under section 13 of the National Health Service Act 2006,
- A Special Health Authority established under section 28 of that Act, or section 22 of the National Health Service (Wales) Act 2006,
- A Primary Care Trust established under section 18 of the National Health Service Act 2006,
- A Local Health Board established under section 11 of the National Health Service (Wales) Act 2006,
- a Health Board within the meaning of the National Health Service (Scotland) Act 1978,
- a Special Health Board within the meaning of that Act,
- the managers of a State Hospital provided under section 102 of that Act,
- a National Health Service trust first established under section 5 of the National Health Service and Community Care Act 1990, section 25 of the National Health Service Act 2006, section 18 of the National Health Service (Wales) Act 2006 or section 12A of the National Health Service (Scotland) Act 1978,
- an NHS foundation trust,
- a Health and Social Services Board established under Article 16 of the Health and Personal Social Services (Northern Ireland) Order 1972,
- a special health and social services agency established under the Health and Personal Social Services (Special Agencies) (Northern Ireland) Order 1990, or
- a Health and Social Services trust established under Article 10 of the Health and Personal Social Services (Northern Ireland) Order 1991<sup>325</sup>.

The DPA applies equally to all relevant records relating to living individuals, and includes private health sector and health professionals' private practice records<sup>326</sup>.

Any requests for access to health records must be made in writing (which includes email).<sup>327</sup> Once the requested fee has been submitted and all the necessary

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<sup>325</sup> Paragraph 69 Data Protection Act 1998

<sup>326</sup> Paragraph 9 DoH Guidance for Access to Health Records 2010

<sup>327</sup> Paragraph 7(2)(a) Data Protection Act 1998

information provided the request for access to the records should be met within 21 days<sup>328</sup> by NHS bodies (or bodies governed by the Department of Health) unless there are exceptional circumstances where it is not possible to comply within this period the applicant should be informed. Other requests for information should be complied with within 40 days<sup>329</sup>.

### ***The Data Protection (Subject Access) (Fees and Miscellaneous Provisions) Regulations 2000***

These Regulations set out the fees to be charged to provide copies of records: -

- Health Records held electronically – maximum charge of £10
- Health Records held in part electronically and in part on other media – maximum charge of £50
- Health Records held totally on other media – maximum charge of £50.

All maximum charges include postage and packaging. Any charges for access requests should not be made in order to make a financial gain<sup>330</sup>.

Where the information is not readily intelligible to the patient, an explanation (e.g. use of abbreviations/medical terminology) must be given<sup>331</sup>.

### ***Access to Health Records Act 1990 (AHRA 1990) – Deceased Person’s Records***

Under AHRA, a health record means a record which:

*‘Consists of information relating to the physical or mental health of an individual who can be identified from that information, or from that and other information in possession of the holder of the record and has been made by or on behalf of a health professional in connection with the care of that individual’*<sup>332</sup>

Those people with a statutory right to apply for access to information contained within a deceased patient’s health records are:

*‘the patient’s personal representative and any person who may have a claim arising out of the patient’s death’.*<sup>333</sup>

The personal representatives do not have to give a reason for applying for access to the health records<sup>334</sup> but they will be required to provide evidence of their identity<sup>335</sup>.

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<sup>328</sup> Paragraph 16 DoH Guidance for Access to Health Records 2010

<sup>329</sup> Paragraph 7(10) Data Protection Act 1998

<sup>330</sup> Paragraph 18 DoH Guidance for Access to Health Records 2010

<sup>331</sup> Paragraph 27 DoH Guidance for Access to Health Records 2010

<sup>332</sup> Paragraph (1) The Access to Health Records Act 1990

<sup>333</sup> Paragraph 3(1)(f) The Access to Health Records Act 1990

<sup>334</sup> Paragraph 38 DoH Guidance for Access to Health Records 2010

<sup>335</sup> Paragraph 40 DoH Guidance for Access to Health Records 2010

If further information is required to confirm the identity of the record holder a request for this should be made within 14 days of the application for access<sup>336</sup>.

Where a copy of a record or an extract is supplied to the applicant, a fee not exceeding the cost of making the copy and (where applicable) the costs of postage shall be required.<sup>337</sup> However paragraph 49 DoH 'Guidance for Access to Health Records 2010', provides that there is no limit to the charges under The Access to Health Records Act 1990, but reiterates that any charge levied should not result in a profit for the record holder.

If no entries have been made to the records within the last 40 days then access should be granted within 21 days however if entries have been made then access should be granted within 40 days.<sup>338</sup>

Access to Health Records may be denied or restricted if it is felt that

- (a) the information is likely to cause serious harm to the physical or mental health of any individual; or
- (b) there is information relating to or provided by an individual, other than the patient, who could be identified from that information; or
- (c) the record or part thereof which was made before the commencement of the Act.<sup>339</sup>

It should be noted that former attorneys and deputies will only be given access to these records if there had a Health and Welfare lasting power of attorney or deputyship. An attorney who acted under an enduring power of attorney will have no right to access medical records or care notes. However some NHS bodies and social services departments will release a personal file to the former main carer.

Despite this, it is possible to argue that the former deputy or attorney is acting in the best interests of the person by asking for such medical records in order to maximise that person's right to any funding that may be available, whether it be for NHS continuing healthcare funding or the NHS funded nursing care.

It is best to make a simple request for access initially because an authority may be willing to grant access.

## **17.6 What to do if access is refused**

The law requires public and private interests in confidentiality to be weighed against the public and private interests of disclosure.

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<sup>336</sup> Paragraph 6 The Access to Health Records Act 1990

<sup>337</sup> Paragraph 4(b) The Access to Health Records Act 1990

<sup>338</sup> Paragraph 3 (5) The Access to Health Records Act 1990

<sup>339</sup> Paragraph 5 The Access to Health Records Act 1990

It has been argued that if a carer requests access to social service or health records on behalf of someone lacking capacity, for the purpose of bringing a potential review on their behalf, access should be given, if there is no suggestion of harm to any person.

***R (on the application of Stevens) v Plymouth County Council & Anor (2002)***  
**EWCA Civ 388 (26<sup>th</sup> March 2002)**

In this case, a mother requested access to her son's records so she could seek advice as to whether to discharge her son from guardianship under the Mental Health Act 1983. The local authority refused on the basis that she had no authority to carry out the necessary balancing exercise between public and private interests in disclosure.

There was no suggestion that letting the mother have access to the records would harm her son or any other person in relation to best interests (i.e. where it is in the best interests of the person lacking capacity that records be disclosed it is right they are).

The Court of Appeal paid particular attention to Article 6 (right to a fair trial) and the need for the mother to have access to take full advice before proceeding with a course of action that would inevitably lead to court proceedings.

### **17.7 How long do records need to be kept**

The length of time that NHS bodies are required to keep records depends on the type of record that is being requested. Guidance is laid down in annex D1 of 'Records Management: NHS Code of Practice' 5<sup>th</sup> April 2006.

The general rules seems to be around 8 years after the conclusion of treatment or death for hospital records however other time periods are specified.

- Occupational health records should be retained for 3 years.
- GP records should be retained for 10 years.
- Mental Health records (under the Mental Health Act 1983) should be retained for 20 years or 10 years after death.

Under current guidance electronic patient records must not be deleted at all.

### **17.8 Obtaining care home records**

The Health and Social Care Act 2008 came into force on 1<sup>st</sup> October 2010. This established a single set of essential standards for all health and adult social care providers who provide a regulated activity to be registered with the Care Quality Commission who will ensure that they are meeting essential standards of quality and safety across all of the regulated activities that they provide.

Regulated activities that require registration are described in the Health and Social Care Act 2008 (Regulated Activities) Regulations 2009 as:

- personal care
- accommodation with nursing or personal care
- accommodation for persons who require treatment for substance misuse
- accommodation and nursing or personal care in the further education sector
- treatment of disease, disorder or injury
- assessment or medical treatment for persons detained under the Mental Health Act 1983
- surgical procedures
- diagnostic and screening procedures
- management of supply of blood and blood-derived products
- transport services, triage and medical advice provided remotely
- maternity and midwifery services
- termination of pregnancies
- services in slimming clinics
- nursing care
- family planning services

The essential standards of quality and safety consist of 28 regulations (and associated outcomes) that are set out in two pieces of legislation: the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010 and the Care Quality Commission (Registration) Regulations 2009. For each regulation, there is an associated outcome, which is the experience people should have as a result of the care they receive.

16 regulations (out of the 28) that come within Part 4 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010 directly relate to the quality and safety of care. Providers must have evidence that they meet the outcomes.

These 16 regulations are set out below:

Regulation	Outcome	Title and summary of outcome
9	4	<p><b>Care and welfare of people who use services</b>                      People experience effective, safe and appropriate care, treatment and support that meets their needs and protects their rights.</p> <p>The Health and Social Care Act 2008 (Regulated Activities) Regulations 2010 states:</p> <p>9 (1) The registered person must take proper steps to ensure that each service user is protected against the risks of receiving care or treatment that is inappropriate or unsafe, by</p>

		<p>means of—</p> <p>(a) the carrying out of an assessment of the needs of the service user; and</p> <p>(b) the planning and delivery of care and, where appropriate, treatment in such a way as to—</p> <p>(i) meet the service user’s individual needs,</p> <p>(ii) ensure the welfare and safety of the service user,</p> <p>(iii) reflect, where appropriate, published research evidence and guidance issued by the appropriate professional and expert bodies as to good practice in relation to such care and treatment, and</p> <p>(iv) avoid unlawful discrimination including, where applicable, by providing for the making of reasonable adjustments in service provision to meet the service user’s individual needs.</p> <p>(2) The registered person must have procedures in place for dealing with emergencies which are reasonably expected to arise from time to time and which would, if they arose, affect, or be likely to affect, the provision of services, in order to mitigate the risks arising from such emergencies to service users.</p>
10	16	<p><b>Assessing and monitoring the quality of service provision</b></p> <p>People benefit from safe, quality care because effective decisions are made and because of the management of risks to people’s health, welfare and safety.</p> <p>The Health and Social Care Act 2008 (Regulated Activities) Regulations 2010 states:</p> <p><b>10</b> (1) The registered person must protect service users, and others who may be at risk, against the risks of inappropriate or unsafe care and treatment, by means of the effective operation of systems designed to enable the registered person to—</p> <p>(a) regularly assess and monitor the quality of the services provided in the carrying on of the regulated activity against the requirements set out in this Part of these Regulations; and</p> <p>(b) identify, assess and manage risks relating to the health, welfare and safety of service users and others who may be at risk from the carrying on of the regulated activity.</p> <p>(2) For the purposes of paragraph (1), the registered person must—</p> <p>(a) where appropriate, obtain relevant professional advice;</p> <p>(b) have regard to—</p> <p>(i) the complaints and comments made, and views (including the descriptions of their experiences of care and treatment) expressed, by service users, and those acting on their behalf,</p>

		<p>pursuant to sub-paragraph (e) and regulation 19,</p> <ul style="list-style-type: none"> <li>(ii) any investigation carried out by the registered person in relation to the conduct of a person employed for the purpose of carrying on the regulated activity,</li> <li>(iii) the information contained in the records referred to in regulation 20,</li> <li>(iv) appropriate professional and expert advice (including any advice obtained pursuant to sub-paragraph (a)),</li> <li>(v) reports prepared by the Commission from time to time relating to the registered person's compliance with the provisions of these Regulations, and</li> <li>(vi) periodic reviews and special reviews and investigations carried out by the Commission in relation to the provision of health or social care, where such reviews or investigations are relevant to the regulated activity carried on by the service provider;</li> </ul> <p>(c) where necessary, make changes to the treatment or care provided in order to reflect information, of which it is reasonable to expect that a registered person should be aware, relating to—</p> <ul style="list-style-type: none"> <li>(i) the analysis of incidents that resulted in, or had the potential to result in, harm to a service user, and</li> <li>(ii) the conclusions of local and national service reviews, clinical audits and research projects carried out by appropriate expert bodies;</li> </ul> <p>(d) establish mechanisms for ensuring that—</p> <ul style="list-style-type: none"> <li>(i) decisions in relation to the provision of care and treatment for service users are taken at the appropriate level and by the appropriate person (P), and</li> <li>(ii) P is subject to an appropriate obligation to answer for a decision made by P, in relation to the provision of care and treatment for a service user, to the person responsible for supervising or managing P in relation to that decision; and</li> </ul> <p>(e) regularly seek the views (including the descriptions of their experiences of care and treatment) of service users, persons acting on their behalf and persons who are employed for the purposes of the carrying on of the regulated activity, to enable the registered person to come to an informed view in relation to the standard of care and treatment provided to service users.</p> <p>(3) The registered person must send to the Commission, when requested to do so, a written report setting out how, and the extent to which, in the opinion of the registered person, the requirements of paragraph (1) are being complied with, together with any plans that the registered person has</p>
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		for improving the standard of the services provided to service users with a view to ensuring their health and welfare.
11	7	<b>Safeguarding people who use services from abuse</b> People are safeguarded from abuse, or the risk of abuse, and their human rights are respected and upheld.
12	8	<b>Cleanliness and infection control</b> People experience care in a clean environment, and are protected from acquiring infections.
13	9	<b>Management of medicines</b> People have their medicines when they need them, and in a safe way. People are given information about their medicines.
14	5	<b>Meeting nutritional needs</b> People are encouraged and supported to have sufficient food and drink that is nutritional and balanced, and a choice of food and drink to meet their different needs.  The Health and Social Care Act 2008 (Regulated Activities) Regulations 2010 states: 14 (1) Where food and hydration are provided to service users as a component of the carrying on of the regulated activity, the registered person must ensure that service users are protected from the risks of inadequate nutrition and dehydration, by means of the provision of— (a) a choice of suitable and nutritious food and hydration, in sufficient quantities to meet service users’ needs; (b) food and hydration that meet any reasonable requirements arising from a service user’s religious or cultural background; and (c) support, where necessary, for the purposes of enabling service users to eat and drink sufficient amounts for their needs. (2) For the purposes of this regulation, “food and hydration” includes, where applicable, parenteral nutrition and the administration of dietary supplements where prescribed.
15	10	<b>Safety and suitability of premises</b> People receive care in, work in or visit safe surroundings that promote their wellbeing.
16	11	<b>Safety, availability and suitability of equipment</b> Where equipment is used, it is safe, available, comfortable

		<p>and suitable for people’s needs.</p> <p>The Health and Social Care Act 2008 (Regulated Activities) Regulations 2010 states:</p> <p>16 (1) The registered person must make suitable arrangements to protect service users and others who may be at risk from the use of unsafe equipment by ensuring that equipment provided for the purposes of the carrying on of a regulated activity is—</p> <p>(a) properly maintained and suitable for its purpose; and</p> <p>(b) used correctly.</p> <p>(2) The registered person must ensure that equipment is available in sufficient quantities in order to ensure the safety of service users and meet their assessed needs.</p> <p>(3) Where equipment is provided to support service users in their day to day living, the registered person must ensure that, as far as reasonably practicable, such equipment promotes the independence and comfort of service users.</p> <p>(4) For the purposes of this regulation—</p> <p>(a) “equipment” includes a medical device; and</p> <p>(b) “medical device” has the same meaning as in the Medical Devices Regulations 2002.</p>
17	1	<p><b>Respecting and involving people who use services</b></p> <p>People understand the care and treatment choices available to them. They can express their views and are involved in making decisions about their care. They have their privacy, dignity and independence respected, and have their views and experiences taken into account in the way in which the service is delivered.</p>
18	2	<p><b>Consent to care and treatment</b></p> <p>People give consent to their care and treatment, and understand and know how to change decisions about things that have been agreed previously.</p>
19	17	<p><b>Complaints</b></p> <p>People and those acting on their behalf have their comments and complaints listened to and acted on effectively, and know that they will not be discriminated against for making a complaint.</p>

20	21	<p><b>Records</b>  People’s personal records are accurate, fit for purpose, held securely and remain confidential. The same applies to other records that are needed to protect their safety and wellbeing. The Health and Social Care Act 2008 (Regulated Activities) Regulations 2010 states:  20 (1) The registered person must ensure that service users are protected against the risks of unsafe or inappropriate care and treatment arising from a lack of proper information about them by means of the maintenance of—  (a) an accurate record in respect of each service user which shall include appropriate information and documents in relation to the care and treatment provided to each service user; and  (b) such other records as are appropriate in relation to—  (i) persons employed for the purposes of carrying on the regulated activity, and  (ii) the management of the regulated activity.  (2) The registered person must ensure that the records referred to in paragraph (1) (which may be in paper or electronic form) are—  (a) kept securely and can be located promptly when required;  (b) retained for an appropriate period of time; and  (c) securely destroyed when it is appropriate to do so.</p>
21	12	<p><b>Requirements relating to workers</b>  People are kept safe, and their health and welfare needs are met, by staff who are fit for the job and have the right qualifications, skills and experience.</p>
22	13	<p><b>Staffing</b>  People are kept safe, and their health and welfare needs are met, because there are sufficient numbers of the right staff.</p>
23	14	<p><b>Supporting workers</b>  People are kept safe, and their health and welfare needs are met, because staff are competent to carry out their work and are properly trained, supervised and appraised.</p>
24	6	<p><b>Cooperating with other providers</b>  People receive safe and coordinated care when they move between providers or receive care from more than one provider.</p>

The other 12 regulations relate more to the routine day-to-day management of a service.

The Care Quality Commission guidance on compliance states that records should be kept as follows:

'Wherever they are relevant to the service, the following records are kept and for the periods of time stated:

- risk assessments; retain the latest risk assessment until a new one replaces it
- Purchasing excluding medical devices and medical equipment; 18 months
- general operating policies and procedures; retain the current version and previous version for three years
- any incidents, events or occurrences that require notification to the Care Quality Commission; three years
- use of restraint or the deprivation of liberty; three years
- detention; three years
- maintenance of the premises; three years
- maintenance of equipment; three years
- electrical testing; three years
- fire safety; three years
- water safety; three years
- medical gas safety, storage and transport; three years
- money or valuables deposited for safe keeping; three years
- staff employment; three years following date of last entry
- duty rosters; four years after the year to which they relate
- purchasing of medical devices and medical equipment; 11 years
- final annual accounts; 30 years."

## Appendix A

### Solicitors for the Elderly Standard Checklist – Is it worth Challenging?

This is to help members discuss the matter with your client at the first interview. It is useful to complete a copy of the Decision Support Tool, based on what the client's needs are. It is useful to know what diagnosis and prognosis has been made, by whom, and when. Although this will not determine eligibility, it may trigger the need for a broader assessment of other domains, which may not otherwise be apparent.

1. Is the person in the last stages of a terminal illness?
2. Consider their **Cognition**: how bad is it. Do they know where they are? Do they know their relatives/friends?
3. What is their **Behaviour** like: is the person difficult to manage. Cross refer to drugs domain as there may be indicators of behaviour problems which are being managed, for example anti psychotic drugs.
4. How do they **Communicate**? It is not sufficient for nursing staff to say that they understand a patient: how do they understand? - is there an objective measure? If they are thirsty do they ask for a drink? Do they tell staff if they are in pain? Or are staff unable to tell whether they are in pain?
5. What are the **Psychological & Emotional needs** of the person? How is this assessed by staff looking after them? Can it be assessed if a person cannot communicate? Do they hallucinate? Do they have a history of depression or other mental illnesses? Cross -refer to drugs domain to check if this pin points a need in this domain.
6. **Mobility**: If mobile, are they at risk of falls? Can the person weight bear? How many members of staff are required to assist them? If they are not mobile- cross- refer to breathing problems and skin integrity, as there is often a link to problems in these domains.
7. **Nutrition and feeding**: Is a person losing weight? Is their weight being monitored? Do they have to have a special diet, or be fed over long periods? Can they swallow? Are they being fed a liquid diet, and why? Is a nutritionist seeing them?
8. **Continence**: Is the person incontinent? Do they suffer from frequent UTIs? Do they have behaviour problems, such as smearing the walls?
9. **Skin viability**: Is the person at risk of pressure sores – The person is more at risk if they are diabetic, low weight or over weight and immobile. Even if there are currently no pressure points, consider whether a person is constantly creamed and turned regularly – remember a well-managed need is still a need.
10. Any **Breathing** problems: e.g. Asthma, COPD, lung cancer. Is it managed and how?

- 11. Medication: Obtain an up to date list-. Identify what these drugs are for and** how often they are taken? Who administers the drugs and who prescribed? For example, many dementia drugs are only prescribed via a memory or mental health clinic rather than the GP service. Does this have to be regularly monitored by medical staff e.g. if on Warfarin, or taking drugs for diabetics. Do they regularly refuse to take medication? Are they taking any prescribed pain relief?
- 12. Altered states of consciousness:** Does the person have ‘vacant’ moments when having a T.I.A? Or Epileptic?

All the above may add up to **Complexity and intensity**

**Appendix B – sample letter requesting an assessment for NHS continuing health care**

**Our Ref:**

**Your Ref:**

**Continuing NHS Health Care Team  
XYZ Primary Care Trust**

Dear Sirs,

**Re Mrs XXX- Eligibility for Continuing NHS health care funding.**

This firm acts for the attorneys for the above named, who resides in The Elms Care Home. Please find enclosed a certified copy of the relevant power.

We believe that Mrs XXX should have been funded by XYZ PCT [*insert date which you are claiming from*] as her care needs are primarily one of health and those needs are more than ancillary and incidental to the provision of accommodation that the local authority could provide under s.21 of the National Assistance Act 1948.

[Set out general details of care history] Mrs XXX was discharged from The General Hospital on the 14<sup>th</sup> February 2008. She suffers from Lewy body dementia and has severe memory loss. She is difficult to manage and can be aggressive. She hallucinates and is anxious much of the time. She has limited communication and cannot make her needs known. She now has problems with her mobility and is unable to hold her head up. She has COPD and so gets recurrent breathing problems. All her care needs are primarily of a health nature.

We believe that Mrs XXX should be assessed for eligibility for continuing NHS health care as her care needs are greater than those of Pamela Coughlan who was held by the Court of Appeal to have care needs that were more than ancillary and incidental to the provision of accommodation which the local authority was under a duty to provide.

We look forward to hearing from you confirming the date you will be undertaking an assessment.

Yours faithfully

**Appendix C- Sample** appeal letter, demonstrating how to tackle each relevant domain band, which should in particular be based on reviewing the client's records, the DST, and assessments which have informed the completion of the DST.

Our Ref:  
Your Ref:

NHS Continuing Health Care Team  
XYZ Primary Care Trust

Dear Sirs,

**Re Mrs XXX- [date of birth] Eligibility for Continuing NHS health care funding.**

Further in this matter, we have been handed copies of the Decision Support Tool for NHS continuing healthcare and would make the following comments:

### **Cognition**

Mrs XXX suffers Lewy Body dementia, which was assessed by Dr Spock from the Memory Treatment Clinic on the 30<sup>th</sup> March 2008. At that point her mini mental state examination showed she scored 15/30. She was re -examined by Dr Mind, Consultant Mental Health Service Older People for the NHS Trust on the 22<sup>nd</sup> March 2009. His letter was sent to Dr Spock on the 22<sup>nd</sup> April 2010 dictated on the 26<sup>th</sup> March 2009). This may be a mistake but it may indicate the letter was sent belatedly for this purpose. That aside, he found that Mrs XXX has a score of 17/30. This would indicate an improvement. There was evidence she was prescribed Aricept in July 2008, which may explain the improvements. In any event the score indicates severe cognitive impairment.

The Decision Support Tool (DST) uses this evidence to score Mrs XXX as having only a high need. The note indicated this was based on a phone call. This was not based on a current scoring or assessment and we therefore challenge it. Mrs XXX has deteriorated significantly since November 2009 from when she has been unable to do simple tasks. She is totally dependent on care staff to anticipate all her care needs, due to her physical and mental state: her memory, awareness, judgement and reasoning are severely impaired. By way of an example, if you asked Mrs XX if she were hungry, she would reply, 'no'. A few minutes later if you asked the same question she would say, 'yes' and if repeated, would answer 'I don't know'.

Dr White in his report dated 9<sup>th</sup> January 2010, states, 'needs supervision for ADLS, remains at high risk of injury if left alone'. It would appear this aspect of the

assessment was overlooked in the completion of the DST. The Nursing Assessment conducted by John Doe, makes no reference to any dementia and therefore is flawed.

## **Behaviour**

The DST states that Mrs XXX has no behavioural needs and ignores in its entirety her extensive history of psychotic symptoms and hallucination. She was becoming increasingly paranoid, anxious and irritable. A letter to Dr Drake dated 6<sup>th</sup> July 2009; indicate that this was evidenced at the reassessment (by an unidentified author). Dr Mind in his letter of the 23<sup>rd</sup> April states in his final paragraph that 'there are a number of difficult behavioural problems'. The Social Services assessment dated 11<sup>th</sup> January 2010 provides more detail of shouting and panic. There is clear evidence from the doctors' letters and the social services report, that Mrs XXX is uncooperative. The Nursing assessment is flawed as no reference has been made to any behavioural problem. This does not mean there are none.

There are a number of reports in the care home's notes as follows: -

[outline dates and specifics as from care home's notes]

Since the date of those letters and assessments, Mrs XXX's behaviour has changed very little, although she is weaker and unable to communicate her fears so strongly. Mrs XXX still cries out when she is moved or lifted and, even though she is so ill, she is still uncooperative.

Even though the care staff say they can understand Mrs XXX a well managed need is still a need.

## **Psychological & Emotional needs**

The DST marks Mrs XXX as falling into the moderate needs band. It does identify her anxiety and hallucinations, which she finds distressing. From the evidence in the notes provided, this would be correctly banded. However, Mrs XXX's emotional needs are hard to explain as she cannot have a meaningful conversation and has a very limited ability to communicate.

## **Communication**

We refer again to Dr Drake's letter dated 22<sup>nd</sup> April 2010; apparently based on an assessment dated 22<sup>nd</sup> March 2009 as this letter states Mrs XXX's speech was normal in flow and form. The date needs to be clarified as, if the assessment was in 2009; before Mrs XXX moved into care then the assessment needs to be up to date, as she will have certainly declined with her diagnosis since that date. The effect of all this is that the DST relied on outdated information.

Mrs XXX clearly has difficulties. The social services report confirms that Mrs XXX is not always lucid and the nurses had told (so therefore not her judgement) her that she is not able to make informed decisions because of her dementia.

Mrs XXX only speaks when spoken to and even then, sometimes the words are incoherent. Any conversation has to be on the most basic level as already mentioned. She has lost complete non- verbal communication. She cannot answer a question with a smile or a frown and there are no facial signs of understanding. She does not use any kind of body or hand communication, but simply stares straight ahead.

### **Mobility**

We consider the DST should have shown her needs were at high level.

The DST fails to pick up on the social services assessment giving a graphic picture of the problems of transfer and the clear risk of falls and Mrs XXX's compromised ability to cooperate. The nursing assessment again fails to record any detail about the problems in transfers and the risk of falls. Dr White in his assessment dated 9<sup>th</sup> January 2010, identifies a 'High risk of falls'. It also states she 'remains at high risk of injury, if left alone'. This is supported by the physiotherapist's report which stated requires a hoist, unable to stand and needs constant supervision for unsupported sitting.

Since the assessment Mrs XXX has deteriorated further. She cannot hold her head up and has no mobility at all. She cannot use the bell to summon help and staff at the care home have been observing her on an hourly basis, day and night, to see whether the temperature of the room is suitable, whether she needs additional clothing, checking continence and fluid intake.

### **Breathing**

Mrs xxx has COPD, which once there does not go away or improve. It is likely to deteriorate. She has regular medication for treatment of this. She also has a trial fibrillation. This diagnosis is reflected in the medical letters, but is not adequately noted in any reports. The social workers report makes reference to atrial fibrillation but not the COPD. Dr White's medical assessment notes 'AF' but not COPD in his report dated 9<sup>th</sup> January 2010. Yet again the nursing assessment fails to acknowledge any problem with this. Although a diagnosis does not mean Mrs xxx is eligible for full NHS funded, the diagnosis and the impact of it should have been taken into account in the DST. It is likely she has moderate care needs in this domain.

Para 23 of the National Framework states that 'the decision as to whether this is the case should look at the totality of the relevant needs'. As there are flaws in the information taken into account in the assessment the outcome is flawed.

Para 35 makes clear that family and/or carers should receive advice and information

to enable them to participate in informed decisions about the future care. It would appear Mrs XXX's family have not been given an opportunity to input into the assessment. Again, indicating the assessment process is flawed.

They should have been given details of the person coordinating the assessment process, but from the notes, this does not appear to have occurred. Again this indicates that the process was flawed.

Mrs XXX's breathing has deteriorated further, which is shallow and weak.

Her current medication is:

Lansoprazole (30 mg) - for stomach

Citalopram 10mg- for her anxiety

Digoxin - for treatment of her COPD

### **Establishing Primary Care Need**

The DST at para 32 notes,

‘A clear recommendation of eligibility to NHS Continuing Healthcare would be expected in each of the following cases:

- A level of priority needs in any one of the four domains that carry this level.
- A total of two or more incidences of identified severe needs across all care domains.

If 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 can also indicate a primary health need.’

**[Note: SFE's webiste contains all reported relevant Ombudsman's reports that may assist]** The Ombudsman's Case No. E.5/02-03 reported in June 2003, regarding a complaint against the former Shropshire Health Authority, concerned a lady with very similar care needs to Mrs XXX. In that case, a nursing assessment of the lady's needs noted that she required full assistance with all her personal tasks including washing, dressing, feeding and toileting. She was also doubly incontinent, was

dependent upon others for her safety, and could only mobilise with assistance. The Ombudsman was advised by her independent clinical assessor that the lady required significant nursing care and it was debatable whether that could properly be regarded as merely incidental or ancillary to the accommodation, which she also needed. Mrs XXX has more care needs than Mrs F's case and is persuasive argument that Mrs XXX should qualify.

Mrs XXX's care needs are primarily one of health and her care needs are more than ancillary and incidental to the provision of accommodation that the local authority could provide under s.21 of the National Assistance Act 1948. All her care needs flow from her dementia and her DVT; COPD and AF- all primarily one of health.

In conclusion, we appeal against your assessment and would like the matter reconsidered in the light of this evidence.

Yours faithfully

## Appendix D

Extract of Checklist Tool:

### Fast Track Pathway Tool for NHS Continuing Healthcare July 2009

#### Notes

1. This tool accompanies the revised National Framework guidance and the revised NHS continuing healthcare Checklist and Decision Support Tool. This is the version to use from the implementation date of the revised National Framework. Please use the tool in conjunction with the revised National Framework guidance.
2. Where an appropriate clinician (see below) considers that a person has a primary health need arising from a rapidly deteriorating condition, which may be entering a terminal phase, with an increasing level of dependency and so should be fast tracked for NHS continuing healthcare, this tool enables the decision to be recorded. The patient may need NHS continuing healthcare funding to enable their needs to be urgently met (e.g. to allow them to go home to die or to allow appropriate end of life support to be put in place).
3. The Fast Track Pathway Tool should be used by an appropriate clinician to outline the reasons for the fast-track decision. Appropriate clinicians are those who are, pursuant to the National Health Service Act 2006, responsible for an individual's diagnosis, treatment or care and are registered medical practitioners (such as consultants, registrars, GPs) or registered nurses. These can include senior clinicians employed in voluntary and independent sector organisations that have a specialist role in end-of-life needs (for example, hospices) where the organisation's services are commissioned by the NHS. Others involved in supporting those with end of life needs, such as in wider voluntary and independent sector organisations, may identify that the individual has needs for which use of the Fast Track Tool would be appropriate. They should contact an appropriate clinician and ask that consideration be given to completion of the tool. In all cases the clinician should have detailed knowledge of the patient's needs. They should also have an appropriate level of knowledge and experience in dealing with the individual's health needs, such that they are able to reasonably comment on whether the individual's condition may be entering a terminal phase.
4. The completed tool should be supported by a prognosis, if available, but strict time limits basing eligibility on an individual being considered to have a specified expected length of life remaining should not be imposed: it is the responsibility of the assessor to make a decision based on the relevant facts of the case.

5. Appropriate clinicians should complete the attached fast-track documentation and set out how their knowledge and evidence about the patient's needs leads them to consider that the patient has
  - (a) a rapidly deteriorating condition, which
  - (b) may be in a terminal phase with an increasing level of dependency.
6. Any necessary evidence should be included, together with a care plan developed as part of the individual's end of life care pathway that describes the immediate needs to be met and the patient's preferences, including those set out in any advance care plan.

### **Primary Care Trusts**

7. Where a recommendation is made for an urgent package of care via the fast-track process, this should be accepted and actioned immediately by Primary Care Trusts (PCTs). It is not appropriate for individuals to experience delay in the delivery of their care package while disputes over recommendations from completed Fast Track Tools are resolved. PCTs should carefully monitor use of the tool and address any specific concerns with clinicians, teams and organisations as a separate matter to arranging the service provision in the individual case.
8. The purpose of the Fast Track Pathway Tool is to ensure that individuals with a rapidly deteriorating condition, which may be entering a terminal phase, are supported to be in their preferred place of care as quickly as possible, without encountering delay while waiting for the full NHS continuing healthcare eligibility process to be completed. It means that the PCT takes responsibility for the care package in order to get the individual to their preferred place as quickly as possible. Once this has happened, the PCT and its partners can proceed, where appropriate, with reaching a decision on longer-term NHS continuing healthcare eligibility. No one who has been identified through the fast-track process as being eligible for NHS continuing healthcare should have this funding removed without their eligibility being reviewed in accordance with the review processes set out in the National Framework. The review should include completion of the Decision Support Tool (DST) by a multidisciplinary team, including a recommendation on future eligibility. This overall process should be carefully and sensitively explained to the individual and, where appropriate, their family. Careful decision making is essential to avoid the undue distress that might result from a person moving in and out of NHS continuing healthcare eligibility within a very short period of time. Where an individual receiving services through use of the Fast Track Pathway Tool is expected to die in the very near future, PCTs should take particular care to consider whether it is appropriate for them to continue to take responsibility for the care package until the end of life.
9. It should be noted that this is not the only way that individuals can qualify for NHS continuing healthcare towards the end of their lives. The DST encourages practitioners to document deterioration (this could include both observed and likely deterioration) in a person's condition to allow them to take this into account when determining eligibility using the DST. However, this should not be used as a means of circumventing use of the Fast Track Pathway Tool when individuals satisfy the criteria for its use. Where deterioration can be reasonably anticipated to take place before the next planned review, including where the individual is presently asymptomatic, this should also be taken into

account in making a decision on eligibility.

10. There may be some situations where the fast-track process is later found to have been inappropriate, for example because the decision was made after an acute episode of a condition which was subsequently found to be treatable. In such situations the completion of the DST may lead to a decision to cease NHS continuing healthcare funding. However, no one who has been identified through the fast-track process as being eligible for NHS continuing healthcare should have this funding removed without the completion of a full DST, taking account of any deterioration that is present or expected. The National Framework states: 'Neither the NHS nor LAs should unilaterally withdraw from an existing funding arrangement without a joint reassessment of the individual and without first consulting one another and the individual about the proposed change of arrangement. Any proposed change should be put in writing to the individual by the organisation that is proposing to make such a change. If joint agreement between the NHS and the LA cannot be reached upon the proposed change, the appropriate disputes processes should be invoked and current funding arrangements remain in place until the dispute has been resolved.'
11. PCTs should audit use of the Fast Track Pathway Tool carefully and discuss any concerns over its use with organisations, clinicians and teams as appropriate. However, this should be carried out separately from decision making in any individual case.
12. PCTs and LAs should operate person-centred commissioning arrangements so that unnecessary changes of provider or of care package do not take place purely because the responsible commissioner has changed from a PCT to a LA or vice versa.
13. Continuing healthcare assessments, care planning and commissioning for those with end-of-life needs should be carried out in an integrated manner as part of the individual's overall end-of-life care pathway. They should reflect the approaches set out in the National End of Life Care Strategy with full account being taken of each patient's preferences through a needs-led approach, including those preferences set out in their advance care plan.
14. The equality monitoring data form should be completed by the patient who is the subject of the Fast Track Pathway Tool. Where the patient needs support to complete the form, this should be offered by the clinician completing the Fast Track Pathway Tool. The clinician should forward the completed data form to the appropriate location, in accordance with the relevant PCT's processes for processing equality data. If the form has not been completed, the referring clinician should be asked to arrange with the patient for it to be completed. However, this should not delay consideration of the fast-track recommendation.

NHS Continuing Healthcare Fast Track Tool  
*To enable immediate provision of a  
package of NHS continuing healthcare*

**The individual fulfils the following criterion:**

A primary health need arising from a rapidly deteriorating condition which may be entering a terminal phase, with an increasing level of dependency.

**Brief outline of reasons for the fast-tracking recommendation:**

Please set out below the details of how your knowledge and evidence of the patient's needs mean that you consider that they fulfill the above criterion. This may include evidence from assessments together with triggers such as diagnosis, prognosis where this is available, together with details of both immediate and future needs and any deterioration that is present or expected.

When outlining reasons why a clinician considers that a person has a rapidly deteriorating condition that may be entering a terminal phase, the clinician should consider the following definition of a primary health need:

Primary health need arises where nursing or other health services required by the person are

(a) where the person is, or is to be, accommodated in a care home, more than incidental or ancillary to the provision of accommodation which a social services authority is, or would be but for the person's means, under a duty to provide;

(b) or of a nature beyond which a social services authority whose primary responsibility is to provide social services could be expected to provide.

*Please continue on separate sheet where needed. This should include the patient's name and NHS number, and also be signed and dated by the referring clinician.*

Name and signature of referring clinician

Date

--	--

Name and signature confirming approval by PCT

Date

--	--



**WHO CARES WHO PAYS?  
FUNDING OF LONG TERM CARE**

**What happens if you go into a care home?**

**Funding of Placement**

The cost of care, if you have a primary health need should be funded free by the NHS. In many cases this should be considered first and you should seek advice about it.

There are other situations where you do not have to pay for your care including: -

**Intermediate care**

If your place in a care home has been arranged as part of a package of "intermediate care" where you are having short-term therapy or treatment, either following a period in hospital, or to avoid you having to go into hospital, it will be free. Such care is time limited and not normally longer than six weeks.

**Aftercare services**

If you have previously been detained in hospital under Section 3 of the Mental Health Act 1983 (this would be for treatment), your residential care may be provided as aftercare under Section 117 of that Act. The Local Government Ombudsman has recommended that Local Authorities which had previously charged for such services, should have taken steps to identify residents who may have been improperly charged and taken steps to reimburse them or their estates.

**Some War Pensioners**

The Veterans Agency, formerly the War Pensions Agency, can pay towards the cost of a care home providing nursing for War Pensions in very specific circumstances. This is for people with a Higher Rate of War Pension.

**Self-Funding Your Care**

If your care needs are ancillary or incidental to the need for accommodation, you will need to fund the cost of your care, if your capital is over £23,250 (England) or £22,500 (Wales) but you will have help towards this from:

**Attendance allowance/disability living allowance** (Helpline 0845 3000336)

The amount changes slightly each year but the higher rate is £73.60 and the lower rate is £49.30 (2011-2012)

**NHS funded nursing care**

The NHS pays a contribution towards the nursing care provided by a registered nurse, where you receive care in a nursing home (RNCC) (£108.70 in England), for 2011/12. In Wales the amount is decided by Local Health Boards.

**Social Services Supported Care**

If you do not have sufficient resources and you are assessed as needing to be cared for in a care home, you will receive help from the social services department of your local authority

- Social services only pay up to a “standard” amount
- Often there is a shortfall and families are asked to pay. This should be resisted whilst legal advice is taken.
- Much of your income (including £1 per week “tariff” income) for every £250 between £14,250 to £23,250 (England) will go towards your fees. In Wales there is no tariff income. If your capital is below £22,500 the Local Authority take the relevant assessed income towards your fees and pay the rest. Above £22,500 you are self funding. Certain income is disregarded including 50% of your occupational or personal pension providing you pass the other 50% to your spouse or civil partner, if they are not living in the same care home. You must be left with £22.30 for your personal expenses in England and £22.00 in Wales for 2011/12.

**Your Home**

When the social services work out what you should pay towards your care, how will your property be treated?

Your property will be disregarded if: -

- Your placement is temporary
- Your home is occupied by your spouse, a partner, former partner or civil partner (except an estranged or divorced partner, former partner or civil partner unless they are a lone parent)
- A relative or family member (from a specified list) who is: -

- Aged 60 or over
- Under 16 and a child whom you are liable to maintain
- Incapacitated (someone in receipt of incapacity benefits or has needs which would qualify for such benefits)

Social Services have discretion to disregard the value of the property if another person, not falling under the above ('a third party') continues to live there. It may be reasonable, for example, to disregard a dwelling's value where it is the sole residence of someone who has given up their own home in order to care for the resident, or someone who is an elderly companion of the resident, particularly if they have given up their own home.

**Other assets disregarded include: -**

- Capital of £14,250 or less (England) £20,500 (Wales) (2011/12)
- Personal possessions, unless purchased with intention of reducing one's capital in the assessment.
- Capital value of a life interest in land or trust fund.
- Capital value on an interest in a personal injury trust including compensation for vaccine damage and criminal injuries.
- Skipton Fund payments to people who have been infected with hepatitis C as a result of NHS treatment with blood or blood products.

**How does all this work?**

**Example**

Mr & Mrs Campling live in a manor house in Shropshire. It is worth £2,000,000. The manor house contains antiques and other valuables worth £100,000. Mr Campling is to move into a care home has savings of £10,000 in his sole name. His wife has £100,000 but in her sole name. Mr Campling has a State Pension. His wife has income from the Family Trust.

Mr Campling will be required to use his State Pension towards his care but will retain £22.30 of it for his personal expenses.

**What about co-owned property?**

Perhaps you own a property with your son or daughter. In this case the value of your share may be nil because it is unlikely that anyone will be prepared to purchase your share on the open market.

Legal advice needs to be obtained and an argument put forward as this is a complex area.

### **What about co-owned savings?**

Social services have no power to demand to see the finances of a spouse or partner of someone going into care however, if there is an account in joint names they can see what the spouse has.

### **Deliberate deprivation of capital or income**

If you give away assets or otherwise dispose of them in order to put yourself in a more favourable position to get social services financial assistance with your care home fees, they may be able to assess you as if you still have the assets.

#### Example

- Mr Jones had £18,000 in a building society.
- 8 weeks before entering a residential home he bought his car for £10,500 which he gave to his son shortly before entering the home.
- Is this deliberate deprivation?
- When Mr Jones bought the car he was in good health and had no expectation of going into care.
- He had a serious stroke one week after making the gift.

This is unlikely to be contested as being a deliberate deprivation in view of all the circumstances.

*Possible action to consider to prepare for the time when you might need long term care*

- Separate jointly owned savings. Did your spouse contribute more to the savings account than you? In those circumstances, it would be proper for you to put more into their account than yours.
- Are you much older than your spouse/partner? Or does one partner suffer ill health that may lead to a need for care? Should you gift some savings to your younger or fitter spouse now?
- Is the house in your sole name? Should it now be put into joint names and if so consider putting it into joint names as Tenants in Common rather than as Beneficial Joint Tenants? In the former case, the death of one co-owner does not automatically mean that his or her share passes to the survivor who may already be in a residential home.

- Review your Wills. If you go into a care home, is it sensible for the Will of your spouse/partner to leave everything to you? It may be appropriate for them to set up a Discretionary Trust so that you can receive capital and income as necessary, but ensure that this is not taken into account in any means test.
- Have you signed a Power of Attorney? These documents put in place trusted people who can act for you in your lifetime in relation to your finances and property. If someone loses mental capacity to deal with their finance and property and they have NOT put into place an Enduring Power of Attorney before 30<sup>th</sup> September 2007 or a Lasting Power of Attorney since 1<sup>st</sup> October 2007, an application has to be made to the Court of Protection to appoint someone to act on behalf of that person. That person will be called a deputy, and is not necessarily a family member. This is a costly exercise in money, time and emotion and means that you will act under the directions of the Court of Protection in everything you do for your relative.
- Consider an Advance Medical Decision (*'living will'*). In circumstances where you have lost mental capacity and can no longer make choices about treatment to keep you alive, a decision made in advance to the medical profession must be taken into account so long it was made when you understood what you were doing, had been offered sufficient and accurate information to make an informed decision and the circumstances and treatment that subsequently arose are those which were envisaged by you. You must not have been subjected to undue influence or have modified the advance decision either verbally or in writing since it was made. See the SFE leaflet on advance medical decisions.

### **Disclaimer**

This Fact Sheet has been prepared to provide you with basic information about paying for care. It is not to be treated as a substitute for getting full and specific advice from a specialist lawyer. Updated May 2011.

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## **Appendix F Useful Contacts**

### **Care Quality Commission**

City Gate, Gallowgate, Newcastle Upon Tyne, NE1 4PA

Tel: 03000 616161

Fax: 03000 616171

Email: [enquiries@cqc.org.uk](mailto:enquiries@cqc.org.uk)

[www.cqc.org.uk](http://www.cqc.org.uk)

### **Parliamentary Health Service Ombudsman**

Millbank Tower, Millbank, London, SW1P 4QP

Tel: 0345 015 4033

Email: [phso.enquiries@ombudsman.org.uk](mailto:phso.enquiries@ombudsman.org.uk)

[www.ombudsman.org.uk](http://www.ombudsman.org.uk)

### **Information Commissioner**

Wycliffe House

Water Lane

Wilmslow

Cheshire

SK9 5AF

Tel: 0303 123 1113/01625 545745

Fax: 01625 524 510

Email: [notifications@ico.gsi.gov.uk](mailto:notifications@ico.gsi.gov.uk)

[www.ico.gov.uk](http://www.ico.gov.uk)

### **Independent Nursing Assessors**

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