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for older people, their families and carers

guide

Information from Counsel and Care: 40

# Continuing healthcare – understanding the assessment process

This guide has been developed to help clarify who may or may not be eligible for NHS continuing healthcare. It attempts to draw a distinction between health and social care, and focuses on health needs that may warrant NHS continuing healthcare funding.

It should be used in conjunction with our guide **Continuing healthcare: should the NHS be paying for the cost of my care?** (guide number 27).

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Counsel and Care is a national charity, however the creation of the Scottish Parliament, and the Welsh and Northern Ireland Assemblies means there are differences in the ways each region cares for and supports older people. The information in this guide applies essentially to England, although there may be similarities with Scotland, Wales and Northern Ireland.

We also produce five separate guides for both Scotland and Wales. These cover the community care assessment of need process, paying care home fees and making a complaint, which are the key areas where the policy and legislation differ significantly from England.

All the guides we publish can be downloaded from [www.counselandcare.org.uk/helping-you/guides](http://www.counselandcare.org.uk/helping-you/guides) or posted to you, by leaving a message on our guide orderline on 020 7241 8522.

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# 1 NHS continuing healthcare

Some people have very complex health needs and so may need specialist care, regular treatment or other support for a long period of time. This long-term care is called NHS continuing healthcare. NHS continuing healthcare is provided free of charge for people aged 18 or over who require a service as a result of frailty, illness, substance misuse, accident or disability. It is a package of care and support that is provided to meet all your assessed needs, including your physical, mental health and personal care needs. The care is arranged and funded solely by the National Health Service (NHS), but can be provided by other agencies.

This care can be provided in a variety of settings, including a residential care home, a nursing home, a hospital, a hospice or in your own home. In some cases, your choice of living environment may be restricted in order to meet complex or intensive medical health needs.

## 2 Background

Previous arrangements for funding long-term care were very complex and lack of clear government guidance led to widespread variations across the country. The closure over a number of years of NHS long-stay wards and community hospitals during the 1980s saw a shift from public to private sector provision in all aspects of healthcare, but especially in the provision of continuing care for priority groups. These included older people, those with learning difficulties, mental illness and physical disabilities. The shift from public to private sector also meant that charges were introduced for services that that NHS once provided free.

During this time, residents either moved back to community housing or into care homes. Those who chose to move into independent sector care homes were funded by the Department of Social Security – through accessing higher rates of Supplementary Benefit/Income Support to pay for their care – and they were **not** assessed as needing care in a care home. Residents in local council homes were financially assessed under the charging rules at the time for their care.

In 1993, local councils took on the responsibility for funding care in independent care homes as well as their own local council homes. Residents could only access help with funding if they were assessed as needing care in a care home. This meant that the local councils were

liable for the fees if they decided that care was needed, otherwise the resident would pay for their own care if they had sufficient financial resources. Who cares for these groups has never been clear, and this has blurred the boundaries of responsibility.

The terms of the NHS Act 1946 and the NHS Act 1948 created further ambiguity. The NHS was to provide long-term care for older people who were sick or infirm, while local councils were to provide residential care and domiciliary care for frail and older people. The distinction between 'infirmity' and 'frailty' is important, since it means the difference between free care from the NHS and services provided by local council social services, which are subject to a means test.

### 3 Present day

The artificial barriers between health (provided by the NHS) and social care (provided by local councils) lie at the heart of the problem in understanding eligibility for NHS continuing healthcare funding. The difference is important because NHS services are free but community care is either chargeable or means tested. There is no legal definition of what healthcare is, however, the NHS continuing healthcare practice guidance states that 'a healthcare 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)'.

There are currently two parallel systems for healthcare funding:

- NHS continuing healthcare
- nursing care for those who do not qualify for NHS continuing healthcare.

If you do not qualify for NHS continuing healthcare, a joint package of care can be provided by your local council social services and by the NHS if you require nursing input. Please see section 10 for more information about the joint package of nursing care and social care support.



If you have neither significant health needs nor require support from a registered nurse you will receive social care support from your local council social services. See section 10.1 for more information.

## 4 The national framework

The implementation of the national framework has created the provision of national criteria for every Strategic Health Authority (SHA) or local Primary Care Trust (PCT) in England to use when deciding who is eligible for NHS continuing healthcare. It is more transparent in its application and hopefully it will improve the 'postcode lottery' of access to NHS continuing healthcare funding.

Previously, each SHA had its own eligibility criteria. This national framework is a common process, with national tools to support decision making – the Checklist, the Decision Support Tool and the Fast Track Pathway Tool. You can find the contact details of your local PCT or SHA by calling NHS Direct on 0845 46 47.

You may wish to download the national framework for NHS continuing healthcare and NHS-funded nursing care from the Department of Health website at:

[www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationPolicyAndGuidance/DH\\_103162](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationPolicyAndGuidance/DH_103162)

### 4.1 Scotland and Wales

Similar national guidance has been published in Scotland. It can be viewed at: [www.sehd.scot.nhs.uk/mels/cel2008\\_06.pdf](http://www.sehd.scot.nhs.uk/mels/cel2008_06.pdf). A draft National

Framework for NHS continuing healthcare has gone through the consultation process in Wales. Until then, publication guidance is still based at a local level.

For more information about how the national criteria works in Scotland and Wales, please see sections 2.2 and 2.3 of our guide **Continuing healthcare: should the NHS be paying for the cost of my care?** (guide number 27).

## 5 Eligibility criteria for NHS continuing healthcare

Eligibility for NHS continuing healthcare depends on whether your primary need is a 'health' need, not a 'social care' need (as described in section 10.2 of this guide). A primary health need signifies that your overall needs are such that, the responsibility for those needs cannot be met by the local council and so must be the responsibility of the NHS. The key indicators below demonstrate a 'primary health need':

- **Nature:** the particular characteristics of a person's needs (including physical, mental health or psychological) and the type of needs; the overall effects of those needs on the individual, including the type ('quality') of interventions required to manage them;
- **Intensity:** both the extent ('quantity') and severity ('degree') of the needs and the support required to meet them, including the need for sustained care or ongoing care ('continuity');
- **Complexity:** how the needs arise and interact to increase the skill needed to monitor and manage the care;
- **Unpredictability:** the degree to which needs fluctuate, creating difficulty in managing needs, and the level of risk to the person'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.

Some people may have a primary health need on the basis of one indicator alone, while others may have a primary health need based on a combination of indicators because of the quality and/or quantity of care required to meet your needs.

## 5.1 What does this mean?

**Nature:** The nature could refer to the **features** of your **particular condition** which are unstable, intractable, involuntary, chronic or persistent, or the **type** of intervention needed to manage the condition might be invasive treatment, palliative care, responsive medication etc.

**Complexity:** Your needs might be complex as a result of the interaction of multiple symptoms, or the secondary effects. This might also refer to the extent of the intervention needed for a single condition. The multiple conditions, treatments and or symptoms require urgent or timed intervention. If this were not to be provided, you would be placed at significant risk.

**Intensity:** This might refer to a chronic condition, which requires a **type** and **level** of care to manage or maintain health-related needs to minimise risks. Or 'intensity' could mean that aggressive behaviour could present significant risk to self or others which requires regular

risk assessments. The interaction of a number of low level needs could increase the overall intensity to a level of a 'primary health need'.

**Unpredictability:** A fluctuating, unstable or rapidly deteriorating condition **which cannot** be reliably anticipated. This includes your physical, mental or psychological health and/or the behaviour which 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 continuously deteriorating physical condition resulting in rapid dependency or short-term life expectancy. You may need timely intervention to manage symptoms, avoid deterioration or distress and minimise risk.

## 6 Checklist

The Checklist is a tool that is used by practitioners to identify whether someone is eligible for a full consideration or assessment for NHS continuing healthcare, indicating a level of need which constitutes a 'primary health need'. This is sometimes referred to as the screening process.

The Decision Support Tool is used when a full consideration of NHS continuing healthcare is required. For further information about the Decision Support Tool, please refer to section 7.

Both the Checklist and the Decision Support Tool are used to assess whether you meet the eligibility criteria. They illustrate the complexity, intensity and unpredictability of the needs required to meet it.

The focus is on 12 care domains, so all the domains on the Checklist must be presented with a tick. If your needs meet or exceed the descriptions given, a full consideration for NHS continuing healthcare assessment is required to be carried out by the multi-disciplinary team using the Decision Support Tool.

However, there is flexibility for you to receive a full assessment even though you may not apparently meet or exceed all the indicated thresholds. If you disagree with the decision not to provide a full assessment, you can request that one is carried out. For more details,

please see section 7.2 of our guide **Continuing healthcare: should the NHS be paying for the cost of my care?** (guide number 27).

A copy of the Checklist is available on the Department of Health's website:

[www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_103328.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_103328.pdf)

A copy of the Decision Support Tool is available on the Department of Health's website:

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## 6.1 Checklist domains

Each of the domains 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;
- Five or more ticks in column B; or one tick in A and four in B;
- or
- One tick in column A in one of the boxes marked with an asterisk (i.e. the domains which carry a priority level of need in the Decision Support Tool or as below.), with any number of ticks in the other two columns.



A priority rating is given to:

- behaviour,
- breathing
- drug therapies and medication: symptom control, and
- altered states of consciousness.

So if your needs exceed description A for one of these categories above, with a minimum of one tick in any other column, B or C, this is sufficient to warrant a full NHS continuing healthcare assessment be carried out. Moreover, if you were not previously awarded NHS continuing healthcare on the basis of need but have a rapidly deteriorating condition which may be entering a terminal phase, you can be **fast tracked** through the system in order to receive the services that you need. The rate of deterioration might mean that you have a 'Primary Health Need'. The completed Fast Track Pathway Tool is sufficient evidence to establish eligibility; therefore no further assessments are required. A prognosis, although not necessary, can help support decision making. Please see section 8 for further information about the fast tracking process.

## 7 Decision support tool

The Decision Support Tool is more in-depth in its approach than the Checklist and is used by health professionals to assess people for a full consideration for NHS continuing healthcare. Unlike the Checklist, it should be used in every case to establish eligibility, unless the Fast Track Pathway Tool is used.

When carrying out this assessment, the requirement is that the multi-disciplinary team consists of a minimum of two assessors. The team should include both health and social care professionals who have knowledge of the person's needs.

The completed tool should build up a picture and capture the complexity, intensity and unpredictability of your medical, physical and mental health condition. Each domain gives a detailed definition of each of the levels of severity, and this has to be completed with a rating:

**N = no needs, L = low, M = moderate, H = high, S = severe and P = priority.**

A priority level is given only to four domains: **behaviour, breathing, drug therapies and medication: symptom control, and altered states of consciousness.**

The score levels below would mean that you meet 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.

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

Please see the 'assessed level of need' grid in section 3.3 that captures the 12 domains on the Decision Support Tool.

## 7.1 \*Behaviour

Human behaviour is complex, hard to categorise, and may be difficult to manage. Challenging behaviour in this domain includes, but is not limited to:

- aggression, violence or passive non-aggressive behaviour
- severe disinhibition
- intractable noisiness or restlessness
- resistance to necessary care and treatment (this may include not cooperating, non-compliance or disagreement)
- severe fluctuations in mental state
- extreme frustration associated with communication difficulties
- inappropriate interference with others
- identified high risk of suicide

A specialist assessment of a person with serious behavioural issues will usually be required. This would include an overall assessment of the risk(s) to the person themselves, to others or to property, with specific attention to aggression, self-harm and self-neglect and any other behaviour(s).

Description	Level of Need
The person displays no evidence of “challenging” behaviour.	No Needs
The person shows some incidents of “challenging” behaviour, but the risk assessment indicates that the behaviour does not pose a risk to self or others or a barrier to intervention. The person is compliant with all aspects of their care.	Low
The person shows “challenging” behaviour that follows a predictable pattern. The risk assessment indicates a pattern of behaviour that can be managed by skilled carers or care workers who are able to maintain a level of behaviour that does not pose a risk to self or others. The person is nearly always compliant with care.	Moderate
The person shows “challenging” behaviour that poses a predictable risk to self or others. The risk assessment indicates that planned interventions are effective in minimising, but not always eliminating, risks. Compliance is variable but usually responsive to planned interventions.	High
The person shows “challenging” behaviour of severity and/or frequency that poses a significant risk to self and/or others. Prompt intervention and skilled response is needed but this might be outside the range of planned interventions.	Severe
The person shows “challenging” behaviour of severity and/or frequency and/or unpredictability that presents an	Priority

immediate and serious risk to self and/or others. Immediate intervention and skilled response is needed at all times because of the seriousness of the behaviour, and risks involved.	
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## 7.2 Cognition

This may apply, but is not limited to, individuals with learning disabilities and/or acquired and degenerative disorders which place them at **risk** of self-harm (including deterioration of health), neglect or exploitation. Where cognitive impairment is indicated, active thought should be given to referral to an appropriate specialist.

Please refer to the National Framework guidance (see section 4 of this guide) about the need to apply the principles of the Mental Capacity Act 2005 in every case where there is a question about a person’s capacity.

Description	Level of Need
The person has no evidence of impairment, confusion or disorientation.	No Needs
The person has cognitive impairment, for example difficulties in retrieving short-term memory, which requires some supervision, prompting or assistance with more complex activities of daily living, such as managing finances and medication, but awareness of basis risks that affect their safety is clear. <b>OR</b> The person has occasional difficulty with memory and decisions/choices requiring support, prompting or assistance, but has insight into their impairment.	Low

<p>The person has cognitive impairment (which may include some memory issues) that requires some supervision, prompting and/or assistance with basic care needs and daily living activities. Some awareness of needs and basic risks is evident. The person is able to make choices appropriate to needs with assistance. However, he/she has limited ability even with supervision, prompting or assistance to make decisions about some aspects of their lives, which would put them at risk of harm, neglect or deterioration in health.</p>	<p>Moderate</p>
<p>The person has cognitive impairment which is likely to include marked short-term memory issues and possible disorientation in time and place. The person has a limited ability to assess basic risks with assistance and finds it extremely difficult to make their own decisions/choices, even with prompting and supervision which places them at high risk of harm, neglect or deterioration in health.</p>	<p>High</p>
<p>The person has cognitive impairment which may include, in addition to lacking short-term memory, problems with long-term memory or severe disorientation. The person is unable to assess basic risks, even with prompting, supervision or assistance and is dependent on others to foresee even basic needs and to protect them from harm, neglect or deterioration in health.</p>	<p>Severe</p>

### 7.3 Psychological and emotional needs

The person’s psychological needs and their impact on the person’s health and wellbeing should be considered during the assessment.

This domain is used to record the person’s psychological and emotional needs and how they contribute to the overall care needs, noting the underlying causes.

Description	Level of Need
The person’s psychological and emotional needs do not	No Needs

have an impact on their health and wellbeing.	
The person has mood disturbance, hallucinations or anxiety or periods of distress, which have an impact on their health and/or wellbeing, but they respond to prompts and reassurance. <b>OR</b> The person requires prompts to motivate themselves towards activity and to engage in care plan and/or daily activities.	Low
The person has mood disturbance, hallucinations, anxiety symptoms or periods of distress which do not readily respond to prompts and reassurance, and have an increasing impact on the person's health and/or wellbeing. <b>OR</b> The person is withdrawn and demonstrates difficulty in engaging in care planning and/or daily activities.	Moderate
The person has mood disturbance, hallucinations, anxiety symptoms or periods of distress that have a severe impact on the individual's health and/or wellbeing. <b>OR</b> The person is withdrawn from any attempts to engage in support, care planning and daily activities.	High

## 7.4 Communication

If you or a relative have communication needs these should be assessed as part of the assessment carried out by the multidisciplinary team. This section relates to difficulties with expression and understanding (not with interpretation of language).

Description	Level of Need
The person is able to communicate clearly, verbally or non-verbally. Has a good understanding of their primary	No Needs

language. May require translation if English is not the person's first language.	
The person needs assistance to communicate their needs. Special effort may be required to ensure accurate interpretation of needs or additional support either visually, through touch or with hearing.	Low
The person is unable to communicate about their needs and is difficult to understand or interpret, even when assisted. Carers or care workers may be able to anticipate needs through non-verbal signs due to familiarity with the person.	Moderate
The person is unable to reliably communicate their needs at any time and in any way, even when prompted. The person has to have most of their needs anticipated because of the inability to communicate with them.	High

## 7.5 Mobility

If you or a relative have difficulties with mobility, it should be covered in this section. Mobility issues such as wandering should be taken into account in the 'behaviour' domain where relevant. Where mobility problems are indicated, a movement and handling and falls risk assessment should be undertaken (in line with section 6.14 of the National Service Framework for Older People, 2001), and the impact and likelihood of any risk factors considered.

Description	Level of Need
The person is independently mobile.	No Needs
The person is able to weight bear but needs some assistance and/or requires mobility equipment for daily living.	Low
The person is not able to consistently weight bear <b>OR</b>	Moderate



<p>The person is completely unable to weight bear but able to assist or co-operate with transfers and/or repositioning.</p> <p><b>OR</b></p> <p>The person is in one position (bed or chair) for the majority of time and is able to cooperate and assist carers or care workers.</p>	
<p>The person is completely unable to weight bear and is unable to assist or cooperate with transfers and/or repositioning.</p> <p><b>OR</b></p> <p>Because of physical harm or loss of muscle tone or pain on movement the person needs careful positioning and is unable to cooperate</p> <p><b>OR</b></p> <p>The person is at a high risk of falls as identified on the risk assessment</p> <p><b>OR</b></p> <p>The person has involuntary spasms or chronic loss of joint movement placing themselves and carers or care workers at risk.</p>	High
<p>The person is completely immobile and/or clinical condition such that on movement or transfer there is a high risk of serious physical harm and where the positioning is critical.</p>	Severe

## 7.6 Nutrition – food and drink

If an older person is at risk of malnutrition, dehydration and/or aspiration (the act of breathing or drawing in), they should be assessed, and any difficulties in managing the risks involved should be supported by a management plan.

Description	Level of Need
The person is able to take adequate food and drink by mouth to meet all nutritional requirements.	No Needs

<p>The person needs supervision, prompting with meals, or may need feeding and/or a special diet.</p> <p><b>OR</b></p> <p>The person is able to take food and drink by mouth but requires additional/supplementary feeding.</p>	<p>Low</p>
<p>The person needs feeding to ensure adequate intake of food and takes a long time (half an hour or more), including liquidised feed.</p> <p><b>OR</b></p> <p>The person is unable to take any food and drink by mouth, but all nutritional requirements are being adequately maintained by artificial means for example via a non-problematic PEG feeding (the creation of a new opening in the stomach for tube feedings).</p>	<p>Moderate</p>
<p>The person has dysphagia (difficulty in swallowing) that requires skilled intervention to ensure adequate nutrition/hydration and to minimise the risk of choking and aspiration (the act of breathing or drawing in) to maintain airway.</p> <p><b>OR</b></p> <p>The person has subcutaneous (beneath the skin) fluids that are managed by the person or specifically trained carers or care workers.</p> <p><b>OR</b></p> <p>The person's nutritional status is "at risk" and may have unintended, significant weight loss.</p> <p><b>OR</b></p> <p>The person has significant weight loss or gain due to identified eating disorder.</p> <p><b>OR</b></p> <p>The person has problems relating to a feeding device (for example PEG) that require skilled assessment and review.</p>	<p>High</p>
<p>The person is unable to take food and drink by mouth. All nutritional requirements taken by artificial means that require ongoing skilled professional intervention or monitoring over a 24 hour period to ensure nutrition/hydration, for example I.V. fluids.</p> <p><b>OR</b></p>	<p>Severe</p>

The person is unable to take food and drink by mouth, with intervention inappropriate or impossible.	
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## 7.7 Contenance

If you or a relative have continence problems, a full continence assessment should be undertaken. During this assessment, any underlying conditions should be considered, including an evaluation of the impact and likelihood of any risk factors.

Description	Level of Need
The person is continent of urine and faeces.	No Needs
The person's continence care is routine on a day-to-day basis.  The person has incontinence of urine which is managed through for example medication, regular toileting, use of penile sheaths etc. <b>AND</b> The person is able to maintain full control over bowel movements or has a stable stoma, or may have occasional faecal incontinence.	Low
The person's continence care is routine but requires monitoring to minimise risks, for example those associated with urinary catheters, double incontinence, chronic urinary tract infection and/or the management of constipation.	Moderate
The person's continence care is problematic and requires timely and skilled intervention beyond routine care.	High

## 7.8 Skin (including tissue viability)

Evidence of any wounds a person has should be given by a member of the multi-disciplinary team completing a wound assessment chart or tissue viability assessment. A skin condition is any condition which affects or has the potential to affect the integrity of the person's skin.

Description	Level of Need
The person shows risk of pressure damage or skin condition.	No Needs
<p>The person shows risk of skin breakdown which needs preventative involvement once a day or less than daily without which skin integrity would break down.</p> <p><b>OR</b></p> <p>The person shows evidence of pressure damage and/or pressure ulcers either with 'discolouration of intact skin' or a minor wound.</p> <p><b>OR</b></p> <p>The person has a skin condition that requires monitoring or reassessment less than daily. Condition is responding to treatment or no longer requires it.</p>	Low
<p>The person is at risk of skin breakdown which needs preventative involvement several times each day, without which skin integrity would break down.</p> <p><b>OR</b></p> <p>The person has pressure damage or open wound(s), pressure ulcer(s) with 'partial thickness skin loss involving epidermis and/or dermis', which is responding to treatment.</p> <p><b>OR</b></p> <p>The person has a skin condition which requires a minimum of daily monitoring/reassessment to ensure that</p>	Moderate

it is responding to treatment.	
<p>The person has pressure damage, open wound(s), pressure ulcer(s) with 'full thickness skin loss involving epidermis and/or dermis', which are not responding to treatment.</p> <p><b>OR</b></p> <p>The person has pressure damage or open wound(s), pressure ulcer(s) with full thickness skin loss involving damage or necrosis to subcutaneous tissue, but not extending to underlying bone, tendon or joint capsule, which is/are responding to treatment.</p> <p><b>OR</b></p> <p>The person has a specialist dressing routine in place which is responding to treatment.</p>	High
<p>The person has open wound(s), pressure ulcer(s) with 'full thickness skin loss involving damage or necrosis to subcutaneous tissue, but not extending to underlying bone, tendon or joint capsule' which are not responding to treatment and require a minimum of daily monitoring/reassessment.</p> <p><b>OR</b></p> <p>The person has open wound(s), pressure ulcer(s) with full thickness skin loss with extensive destruction and tissue necrosis extending to underlying bone, tendon or joint capsule' or above.</p> <p><b>OR</b></p> <p>The person has multiple wounds which are not responding to treatment.</p>	Severe

## 7.9 \*Breathing

Description	Level of Need
The person has normal breathing and no issues with shortness of breath.	No Needs
The person has shortness of breath which may require the	Low

<p>use of inhalers or a nebuliser and has no impact on daily living activities.</p> <p><b>OR</b></p> <p>The person has episodes of breathlessness that readily respond to management and have no impact on daily living activities.</p>	
<p>The person has shortness of breath which may require the use of inhalers or a nebuliser and limit some daily living activities.</p> <p><b>OR</b></p> <p>The person experiences episodes of breathlessness that do not respond to management and limit some daily living activities.</p> <p><b>OR</b></p> <p>The person requires any of the following:</p> <ul style="list-style-type: none"> <li>• low-level oxygen therapy (24%)</li> <li>• room air ventilators via a facial or nasal mask</li> <li>• other therapeutic appliances to maintain airflow.</li> </ul> <p><b>OR</b></p> <p>The person requires a ventilation device that blows a gentle stream of air into the nose during sleep to keep the airway open, known as Continuous Positive Airways Pressure (CPAP).</p>	Moderate
<p>The person is able to breathe independently through a tracheotomy that they can manage themselves, or with the support of carers or care workers.</p> <p><b>OR</b></p> <p>The person has breathlessness due to a condition that is not responding treatment and limits all daily living activities.</p>	High
<p>The person has difficulty in breathing, even through a tracheotomy, which requires suction to maintain airway.</p> <p><b>OR</b></p> <p>The person demonstrates severe breathing difficulties at rest, in spite of maximum medical therapy.</p>	Severe
<p>The person is Unable to breathe independently and requires invasive mechanical ventilation.</p>	Priority

## 7.10 \*Drug therapies and medication: symptom control

A person's experience of how their pain and other symptoms are managed and the intensity of those symptoms must be considered. Where this affects other aspects of the person's life, the other domains must be referred to, in particular, the psychological and emotional domains. Where the person is receiving their care, this may be in a care home or at home for example, will influence who gives the medication. In determining the level of need, it is the knowledge and skill required to manage the clinical need that is the determining factor. In some situations, an older person or their carer will be managing their own medication and this can require a high level of skill.

Description	Level of Need
The person's symptoms are managed effectively and without any problems, and medication does not result in any unmanageable side-effects.	No Needs
The person requires supervision with administration of and/or prompting with medication or the person may have a physical, mental state or cognitive impairment requiring support to take medication, but shows compliance with medication routine. <b>OR</b> The person is experiencing mild pain that is predictable and/or is associated with certain activities of daily living. The person's pain levels and other symptoms do not have an impact on how care is provided.	Low
The person requires the administration of medication	Moderate

<p>due to:</p> <ul style="list-style-type: none"> <li>• Not cooperating- or non-compliance,</li> <li>• Type of medication (for example insulin), or</li> <li>• Route of medication (for example PEG, liquid medication).</li> </ul> <p><b>OR</b></p> <p>The person is experiencing moderate pain which follows a predictable pattern; or has other symptoms which are having a moderate effect on other domains or on how care is provided.</p>	
<p>The person requires support with administering and monitoring of their medication routine by a registered nurse or care worker specifically trained for this task, because of potential fluctuation of the medical condition or mental state, or risks regarding the effectiveness of the medication or side-effects. It is usually not problematic to monitor the condition.</p> <p><b>OR</b></p> <p>The person is experiencing moderate pain or other symptoms which is/are having a significant effect on other domains or on how care is provided.</p>	High
<p>The person requires support with administering and monitoring of their medication routine by a registered nurse or care worker specifically trained for this task, because of potential fluctuation of the medical condition or mental state, or risks regarding the effectiveness of the medication or side-effects. Even with monitoring the person's condition, it is usually problematic to manage.</p> <p><b>OR</b></p> <p>The person has severe recurrent or constant pain which is not responding to treatment.</p> <p><b>OR</b></p> <p>The person is at risk of non-cooperation with medication, placing them at severe risk of relapse.</p>	Severe
<p>The person has a drug regime that requires daily monitoring by a registered nurse to ensure effective</p>	Priority



symptom and pain management associated with a rapidly changing and/or deteriorating condition. <b>OR</b> The person has constant and overwhelming pain despite all efforts to control pain effectively.	
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## 7.11 \*Altered states of consciousness (ASC)

The evidence of whether a person has altered states of consciousness at a priority level of need should come from the comprehensive multidisciplinary team assessment of a person's care needs. This should encourage consistent decision-making. This is to be used together with any evidence from a risk assessment.

Description	Level of Need
The person shows no evidence of altered states of consciousness (ASC).	No Needs
The person has a history of ASC which is effectively managed and so is at a low risk of harm.	Low
The person has occasional episodes of ASC that require the supervision of a carer or care worker to minimise the risk of harm.	Moderate
The person has frequent episodes of ASC requiring supervision of a carer or care worker to reduce the risk of harm.	High
The person is in a coma. <b>OR</b> The person shows evidence of ASC that occurs on most days, and does not respond to preventative treatment, resulting in a severe risk of harm.	Priority

## 7.12 Assessed levels of need

The grid below captures the results of the Decision Support Tool. The final result should be compared against the criteria in section 7 to see whether the eligibility criterion has been met.

Care Domain	P	S	H	M	L	N
*Behaviour						
Cognition						
Psychological Needs						
Communication						
Mobility						
Nutrition – Food and Drink						
Continence						
Skin (including tissue viability)						
*Breathing						
*Drug Therapies and medication: Symptom control						
*Altered States of Consciousness						
<b>Other significant care needs</b>						
<b>Totals</b>						

Does not have a priority or severe rating for the domain shown

## 7.13 Building evidence to support eligibility

It is important to remember that the Decision Support Tool should be used in conjunction with the comprehensive assessment framework. This means that the multi-disciplinary team should ensure that they have, in the first instance, obtained evidence from all the necessary

assessments for example, comprehensive, specialist, Person-Centred Plans for Learning Disability and the Care Programme Approach used to mental health patients, appropriate to the care group concerned and in line with the core values. These assessments will help build an evidence base which will highlight your care needs. Often a person is denied NHS continuing healthcare funding as a result of wrong or insufficient information contained in the assessment about the nature of the person's care needs. This will enable the professionals to make the right judgement, backed up with evidence as to why that level has been chosen.

If you have needs that do not automatically fall into the identified 11 domains, there is space on the assessment for these needs to be recorded separately (the twelfth care domain) in the level of need - Low, Moderate, High and Severe. Evidence from risk assessments should also be taken into account when deciding whether a recommendation of eligibility should be made, for example, behaviour, mental health or skin integrity. For more details about the assessment process, please see our guide **Assessment and services from your local council in England** (guide number 12).

## **7.14 Mental health needs**

If you have dementia or any other mental health needs, it is important to make sure that this is recorded on your assessment, with details about your condition from a psychiatrist or another mental health specialist, such as a community psychiatric nurse (CPN).

## 7.15 Eligibility

Generally, to be considered eligible your care needs must be at a level where you would require 24-hour care. The multi-disciplinary team will look at your care needs at any given time, the interaction of those needs that might make the care more difficult or complex to handle and the skilled intervention required to manage them, not the general diagnosis.

Once the multi-disciplinary team has reached the decision about eligibility, this recommendation should be made to the Primary Care Trust (PCT). Only in exceptional circumstances, and for clearly articulated reasons, should the multi-disciplinary team's recommendations not be followed. You should be given a copy of the completed assessment along with a written outcome outlining the reason why the criteria has or has not been met in your case.

## 8 Fast tracking

If your friend or relative is nearing the end stages of their life, and has an increasing level of dependency due to a rapidly deteriorating condition, they will need a package of care to be put in place urgently. This will help them stay in the place that they prefer to be, which could be their own home, a care home or another setting. If they need this, they can be 'fast-tracked' for immediate provision of NHS continuing healthcare, using the 'Fast Track Pathway Tool'.

The Fast Track Pathway Tool should make sure that anyone in such a situation is supported to receive care in their preferred place as quickly as possible. The Fast Track Pathway Tool may be used by a ward sister, consultant or GP responsible for you, or your relative's diagnosis, treatment or care, to outline the reasons for the fast-tracking decision. This can be supported by a prognosis, but note that strict time-limits are not relevant for end-of-life care and should not be imposed.

It is the responsibility of the assessor to make a decision based on the relevant facts of a person's case. If possible, the initial fast-tracking decision should be followed by a full assessment of the person's needs, including any psychological, emotional, mental health and physical needs.

A copy of the Fast Track Pathway Tool is available on the Department of Health's website:

[www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_103327.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_103327.pdf)

If a recommendation is made for an urgent package of care using the Fast Track Pathway Tool, the Primary Care Trust (PCT) should accept it and the proposed care package should be arranged within forty eight hours. A person should not experience delay in receiving care when there are disputes about eligibility.

'End-of-life' care can be provided in a variety of settings including a hospital, in a hospice, in a care home, and in someone's own home. You or your relative should be able to choose to remain living in a residential care home or a nursing care home if your needs can continue to be met in full, with external support when required.

Good practice is currently supported through a National End-of-Life Care Strategy. Continuing healthcare funding complements the strategy because the focus of both is on the person. You, or your relative's needs, and how and where you or they would prefer to be supported, should be kept at the heart of the process and the process should be explained to you or your relative in a careful and sensitive way.

## 9 How long does NHS continuing healthcare last?

Eligibility for NHS continuing healthcare funding is **not permanent**. A review of your needs should be carried out after three months of you first receiving the funding, and then on a yearly basis thereafter. If your needs have stabilised or improved, you may no longer need this level of care.

If you are assessed as no longer needing this level of care, you can ask for a review of the decision. It is important to ask for the decision to be looked at again, if you feel that the assessment was not carried out correctly, if they failed to take all your health needs into account, or it may be that your health is still deteriorating. For more information about the review process, please see our guide **Continuing healthcare: should the NHS be paying for the cost of my care?** (guide number 27, section 7.2 onwards).

The national framework says (page 40): *“Neither the NHS or the local council 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. Alternative funding arrangements should first be agreed and put into effect. Any proposed change should be put in writing to the individual 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 current funding arrangements should remain in place until the dispute has been resolved.”*



## 10 Joint package of care

If you live in a nursing care home and do not meet the eligibility criteria for NHS continuing healthcare, the cost of your nursing care needs will be funded by the NHS through the 'free nursing care' payment. You must be assessed by a registered nurse to see if you have nursing needs.

If you are assessed as eligible for the free nursing care payment you will receive £108.70 if you live in England and £120.55 per week if you live in Wales.

The payment from the NHS covers nursing costs and is deducted from the full cost of the care home placement. It is paid direct from the NHS to the care home.

If you have nursing needs but do not require a move to a nursing home, you will not receive the free nursing care payment but will be supported by a community nurse or another health professional who will visit you in your home or community accommodation. This may be sheltered or extra care housing.

In both of the above cases, you will then be financially assessed to determine how much you will pay towards your social care needs (and accommodation needs in a care home). For more information

on how the local council financially assesses you to determine how much you will pay for the cost of your care, please see our [guide 16: Care home fees: paying them in England](#) .

## **10.1 Care support from the local council social services**

The local council social services is responsible for arranging and funding social care for those people whose needs do not meet the eligibility criteria for NHS continuing healthcare. If your needs would be met through community or social care rather than nursing care, you will be financially assessed by your local council social services to determine how much you will contribute towards your care.

## **10.2 What is social care?**

Social care is a term that means services and assistance for (including gaining and maintaining independence) vulnerable groups in society, such as some older people, people with disabilities (physical, sensory or learning), people with mental health problems, and people with problems arising from the use of drugs or alcohol, and asylum seekers.

The primary responsibility for social care rests with the local council social services. Depending on your needs, care services can include residential or nursing accommodation as well as care in your home and services enabling you to continue to live in the community.

See below for examples of the type of services that can be provided by the local council social services:

- Washing and dressing
- Assistance with toileting
- Assistance with mobility
- Emptying the commode
- Washing up
- Supervision and monitoring of medication
- Laundry
- Turning the bed
- Preparing meals and monitoring eating
- Arranging day care and befriending services
- Combing hair and brushing teeth
- Advice and information
- Assistance with transferring to bed, chair and so on.

In contrast, the NHS has a general duty to provide medical and nursing services and to prevent illness, care of people who are ill, and aftercare for people who have been ill. The NHS will continue to be responsible for providing healthcare through primary care services and specialist community health service such as physiotherapy, speech and language therapy, occupation therapy, dietetics, community nurses and continence services. **The important distinction is that local councils are currently prohibited from**

providing or arranging services carried out by a registered nurse or any health service professional.

Our advice workers can advise on a wide range of issues affecting older people, their families and carers. Counsel and Care produce a range of guides which can be downloaded from our website [www.counselandcare.org.uk](http://www.counselandcare.org.uk), or by leaving a message on our guide order line on 020 7241 8522.

This guide is not a full explanation of the law and is aimed at people over 60.

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