

## How-to-guide

### Seeking funding for care required during an extended hospitalisation

This guide has been written to help disabled people and people with particular care needs who have been admitted to hospital understand what care and support they may be able to receive in hospital, either from the NHS or their local authority, if the hospital is not meeting all of their needs.

This guide has been prepared with input from law firm Leigh Day and is intended to provide an overview of the relevant law and guidance to help people who are unsure of what additional support they can request when they are in hospital for an extended period of time. This guide was prepared in October 2023 and reflects our understanding of existing provisions at this time. This guide is not intended to be used in legal action, and if you are considering legal action relating to the care and support you are receiving in hospital, then you should seek specialist legal advice.

#### **1. Why might I require funding for care during a stay in hospital?**

If you are receiving treatment in hospital, you may have needs that are not being met by the hospital. You may require additional support in order for these needs to be met. Some examples of these needs might be:

- Needing help with communicating, including communicating any pain you might be in.
- Needing help with personal care above what can be provided by general NHS staff (for example needing 24/7 care or monitoring).
- Needing care from a 'known carer' (i.e. a carer who knows you well), someone who understands your unique and specific needs, and the history of your health and care needs. The need for a 'known carer' may also be relevant to your communication needs, if only certain people understand how you communicate certain things.
- Needing help to maintain your emotional wellbeing and social needs during a hospital stay, including in order to access things that will make your stay in hospital more bearable and help you engage with family and friends.

Prior to entering hospital, you may have used benefits such as Personal Independence Payment (PIP), to meet these needs. However, if you are in hospital for an extended period of time you may no longer be entitled to PIP for the time you are in hospital. This applies to both the daily living component and mobility component of PIP (see s. 29(1) The Social Security (Personal Independence Payment) Regulations 2013).

The relevant legal framework states that if a ‘person is undergoing medical or other treatment as an in-patient at a hospital or similar institution in which any of the costs of the treatment, accommodation and any related services provided for the person are borne out of public funds’ (for example, if you are being treated by the NHS), then PIP will not be payable if either:

**A)** That person is an in-patient for a period of 28 days or more (see: reg 29 and reg 30(1) The Social Security (Personal Independence Payment) Regulations 2013).

**B)** That person is treated as an in-patient multiple times, there is no more than 28 days between each admission, and the total time spent as an inpatient amounts to 28 days or more (see: reg 32(4) The Social Security (Personal Independence Payment) Regulations 2013).

The suspension of PIP whilst you are in hospital also means that any associated benefits, like Carer’s Allowance, will stop (so, if you have a carer who claims Carer’s Allowance for the care they give you, they will no longer be able to claim this if your PIP is suspended due to extended hospitalisation).

Not receiving benefits such as PIP and Carer’s Allowance may mean that you are unable to fund care and support that continues to meet your needs. However, if you are eligible for either NHS Continuing Healthcare or are eligible to receive support from your local authority, then you may be able to request funding for the care you require during your hospitalisation.

## **In summary**

If you are eligible for NHS Continuing Healthcare, and your needs are not met by the hospital, your Integrated Care Board (ICB) has a duty to assess your needs and provide a package which meets your assessed health and social care needs (see Part 2).

If you have been assessed as meeting the eligibility criteria for care and support by your local authority, then the local authority continues to have a duty to meet your ‘eligible needs’, if these are not being met by the NHS (see Part 3, including for further information about what ‘eligible needs’ are).

If you think you need support for your health or care needs but have not had an assessment, or you think your needs have changed following your admission to hospital, you should contact your local authority to ask for a needs assessment or re-assessment (as applicable).

## **2. I am entitled to NHS Continuing Healthcare, what support can I get whilst in hospital?**

If you are eligible for NHS Continuing Healthcare, then the NHS is under a duty to provide you with a package which meets all of your 'assessed health and associated social care needs'. This duty is set out in the 'The Framework for NHS Continuing Healthcare and NHS-Funded Nursing Care' (The National Framework), at paragraphs 5, 55 and 192.

The part of the NHS which should provide this package is called an Integrated Care Board (ICB). It is the responsibility of an ICB to manage the NHS budget, and decide which health services to provide in order to meet the health needs of the population within its area of responsibility.

The NHS continues to have a duty to provide a package which meets all of your 'assessed health and social care needs' when you are in hospital. The National Framework states that 'NHS Continuing Healthcare may be provided in any setting' (paragraph 64). This means that if you are in hospital and your assessed health and social care needs are not being met through the general care you are receiving in hospital, you can seek additional support through NHS Continuing Healthcare.

The care and support you are entitled to is not limited to care needed for your physical health. As set out above, the care the NHS is under a duty to provide extends to all your 'assessed health and associated social care needs'. Paragraph 53 of The National Framework explains that the reference to 'social care needs' relates to the Care Act 2014 eligibility criteria (which are set out in further detail in The Care and Support (Eligibility Criteria) Regulations 2015). Some examples of the needs set out in these Regulations include being able to maintain family or other personal relationships, and making use of necessary facilities or services in the local community including public transport, and recreational facilities or services. Therefore, if your social and emotional needs form part of the needs your ICB has assessed you as having, then those needs should be met through your Continuing Healthcare package. If the ICB has not included an assessment of these needs in your assessment, you should consider asking to be re-assessed.

If you are not sure what your assessed needs are, you should ask to see your NHS Continuing Healthcare Care Plan. Paragraph 189(a) of the National Framework explains that you should have a personalised Care Plan which sets out what your assessed needs are, and that this should be drawn up with you involved.

The National Framework also sets out that your care and support package should be kept under a regular review and that your needs need to be reviewed if they change (paragraph 201). Reviews should focus on whether your care plan or arrangements are appropriate to meet your needs (paragraph 203). If your needs change (for example because you are in a new setting/ or have fallen ill) then your needs should be assessed, and the package must be updated accordingly to ensure that your needs are met.

Your needs could be met through NHS Continuing Healthcare in different ways. For example, your care package could be delivered through a Personal Health Budget. A Personal Health Budget is an amount of money which is allocated to you to support your needs. Personal Health Budgets can be given to you in different ways. For example, in some circumstances you could be given a cash payment (this is called a 'direct payment'), a payment could be given to a third party who will handle the money on your behalf, or the NHS could remain responsible for the money and use it to make arrangements for care and support which you have agreed to.

In summary, if you are eligible for NHS Continuing Healthcare, the NHS has a duty to meet your assessed health and associated social care needs. The NHS has a duty to continue meeting these needs if you are admitted to hospital and should assess your needs and update your care package to ensure your needs continue to be met during your time in hospital.

### **3. I have been assessed as having 'eligible needs' by my local authority, what support can I get whilst in hospital?**

Under the Care Act 2014, a local authority is also under a duty to assess an adult's needs for care and support. This means that even if you are not eligible for Continuing Healthcare, if your local authority believes you may have needs for care and support, then the local authority must assess whether you do have those needs and what those needs are (see s.9(1) Care Act 2014).

If you have been assessed as having 'eligible needs' (these are the needs identified during your needs assessment) then s. 18 Care Act 2014 states that your local authority will be under a duty to meet those needs. Depending on factors such as your financial means, the local authority may be able to charge you for the care and support it provides to meet your needs.

If you are assessed as having eligible needs then a local authority will draw up a care and support plan (or support plan) with you. Section 27 of the Care Act 2014 puts the local authority under a duty to review your care and support plan (or support plan) and if you make a reasonable request to have the plan reviewed, the local authority should review the plan. If your circumstances have changed and this affects the care and support you require (for example because your hospital admission means you require different care), then the local authority is under a duty to carry out an assessment and revise your care and support plan accordingly.

Section 22 of the Care Act 2014 sets out certain limits on the types of needs which local authorities are able to meet. If the NHS should be providing care and support to meet health needs, then the local authority is not allowed to provide the support. If in the course of a needs assessment, a local authority identifies needs which could be met by another agency (for example, the NHS), then paragraph 48 of the National Framework states that the local authority should refer you to the other agency. However, if the NHS is not meeting your needs, then your local authority is not prevented from stepping in to meet them.

By section 18(7) of the Care Act 2014, the duty to meet eligible needs does not apply to those needs being met by a carer. However, if the carer cannot meet the needs without local authority support (e.g. without their travelling expenses to the setting where the care is required being met) then that support must be provided. If a carer involved in your care (for example, a family member) is unwilling to provide the pay without some support, they should clearly say this.

A local authority can meet your needs through a personal budget. This is different from a personal health budget, because it is designed to meet your social care needs and is provided by your local authority, rather than the NHS. Section 26 of the Care Act 2014 explains that a personal budget is a statement which outlines the costs to the local authority of meeting your needs and the amount which you are required to pay towards those costs.

The money in your personal budget can be managed in different ways. For example, the local authority could source the care and support you need directly, or you can request a direct payment. To receive a direct payment you must meet a number of requirements outlined in [section 31 of the Care Act 2014](#). For example, the local authority must be satisfied that you can manage direct payments either by yourself or with help that the local authority thinks you or another person who is managing your direct payment can access.

In summary, if you have been assessed as having 'eligible needs' by your local authority then the local authority is under a duty to meet those needs, unless your needs should be being met by an NHS service. If a carer cannot meet your needs without local authority support, then the local authority must provide the support needed for your carer. Your local authority should have a care and support plan (or support plan) in place, keep it under review, and if you make a reasonable request for the local authority to review the plan, they should review and if necessary, amend the plan.

Step-by-step: how to ask your ICB or local authority for additional support

If you are eligible for NHS Continuing Healthcare, write to your ICB outlining why support is required when you are in hospital to meet your assessed needs. If you are not sure of your eligibility, ask for an assessment.

If you are NOT eligible for NHS Continuing healthcare, write to your local authority outlining why support is required when you are in hospital to meet your assessed needs.

Ideally, arrangements will be put in place in your care/support plan before any hospitalisation to plan for what steps should be taken if you are hospitalised and to ensure your needs there are assessed and met. If this is not done, you should request an assessment when you are in hospital to ensure your needs there are assessed and met.

## **4. Step-by-step: how to ask your ICB or local authority for additional support**

- If you are eligible for NHS Continuing Healthcare, write to your ICB outlining why support is required when you are in hospital to meet your assessed needs. If you are not sure of your eligibility, ask for an assessment.

- If you are NOT eligible for NHS Continuing healthcare, write to your local authority outlining why support is required when you are in hospital to meet your assessed needs.
- Ideally, arrangements will be put in place in your care/support plan before any hospitalisation to plan for what steps should be taken if you are hospitalised and to ensure your needs there are assessed and met. If this is not done, you should request an assessment when you are in hospital to ensure your needs there are assessed and met.

Key points to highlight when making this request:

- Request an updated assessment of your needs in hospital to support your position that your needs are not being met.
- Identify the need that is not being met by the hospital and set out clearly what is needed to meet this need and why. Point to any documents from your ICB or local authority which recognise this need. For example if you require a known carer to help you in hospital you could say: 'My care plan recognises that I require a known carer in order to communicate effectively. Without assistance from a known carer my communication is simply not understood. My known carer is not able to be with me in hospital without additional support because the travel expenses are too high.'
- Highlight any limitations preventing your current support package from operating as it should. For example, 'it is unreasonable to expect my personal assistants to travel 2 hours every day to deliver the care I need.'
- Don't disregard non-physical needs if they are part of your care/support plan and included in your 'assessed' needs. This includes emotional and social needs.
- Explain why your need arises from your disability and explain that meeting this need constitutes a reasonable adjustment. Under the Equality Act 2010, public bodies, such as the NHS, must make reasonable adjustments for disabled people. Guidance from Public Health England explains that people with learning disabilities may rely on family carers and need support to communicate and that the NHS has a responsibility to ensure disabled people can properly access NHS services. The NHS suggests adding information to your 'summary care record' so that medical staff are aware of what reasonable adjustments you need. You could refer to your summary care record when asking for additional support.

- If applicable, refer to the The LeDeR Programme, (Learning from lives and deaths - People with a learning disability and autistic people). [The 2021 LeDer Report](#) highlights the continuing need for providers caring for individuals with learning disabilities to ensure they make reasonable adjustments. Page 49 of the report describes examples of best practice, such as involving family carers, supporters and the person with a learning disability themselves in healthcare decisions. Page 54 of the report also highlights the benefit of a learning disability liaison nurse for people with a learning disability who are admitted to hospital. The [NHS England website](#) explains that a learning disability nurse is a specialist nurse who supports you if you have a learning disability while you are in hospital. If you have already been admitted to hospital you could ask if they have a learning disability nurse. If your GP is referring you to hospital you may be able to ask to go to a hospital which has a learning disability nurse.
- Refer to the [recommendations of Healthwatch England](#) which explain that the NHS should ensure people who have communication needs are given healthcare in the way that they need it, namely in a way that is accessible to them.

## **5. What to do if your initial request for additional care and support is refused.**

Your request may be refused for one of the reasons set out below. We have suggested some potential responses to refusals of your request.

### **‘My ICB said I was not entitled to NHS Continuing Healthcare whilst I was in hospital’**

Potential response: You could explain to your ICB that paragraph 64 of the National Framework states that ‘NHS Continuing Healthcare may be provided in any setting’ and is not limited to situations outside hospitals. You should then reiterate that you have assessed health and/or social care needs which the ICB is under a duty to meet and which are currently not being met in hospital. You may want to refer to your care plan when stating what needs are not being met.

For example: “I have been assessed as being eligible for NHS Continuing Healthcare and my assessed needs include a need for a known carer to help with my communication, because only someone who knows me well is able to understand me and help me communicate. My communication difficulties and need for a known carer to help with communication are outlined in my care plan (if possible, refer them to the relevant excerpt / page of your care plan). Currently the care I am receiving in hospital doesn't include help with communication from a known carer, and this is having a negative impact on my wellbeing and means I am unable to communicate important information, such as my pain levels, to medical staff.”

**‘My ICB said that I was not able to use NHS Continuing Healthcare to pay for care from a family member’.**

Potential response: There are restrictions on using your direct payments to pay family members (see [The National Health Service \(Direct Payments\) Regulations 2013](#) as amended by [The National Health Service \(Direct Payments\) \(Amendment\) Regulations 2017](#)). However, you could still ask your ICB to consider your request for a family carer, on the basis that it is necessary to meet your needs. For example, you could say:

“I understand there are regulations concerning using direct payments to pay for care from a family member. However, in my case, it is necessary that [name person] provides my care because they have specialist knowledge of my condition and are able to meet my care needs, including being able to identify when I am in pain or when my condition is worsening. Only someone who knows me well will be able to properly identify these changes. A person who does not have the specific knowledge of my condition would not be able to meet my needs. Paragraph 153 of the NHS England [‘Guidance on direct payments for healthcare: Understanding the regulations’](#), states that a direct payment can be used to pay a family member ‘if the ICB is satisfied that this is necessary to meet the person receiving care’s need for that service’. As I have outlined, it is necessary to have [name person] provide my care in order to meet my assessed needs.”

**‘My ICB said they could not fund care required to meet my emotional or social needs’ or ‘My ICB said it is the responsibility of the local authority to meet my social care needs’.**

Potential response: If your emotional and social needs are needs which the ICB assessed you as having, then they are under a duty to meet those needs. It may help to refer to your Care Plan when responding to the ICB and you can also point them to the relevant legislation which says they are under a duty not only to meet your assessed health needs, but also your associated social care needs. For example, you could say “I require help from a known carer when I am in hospital, because I become distressed in unfamiliar settings and my known carer is able to help me communicate with medical staff and also access activities that help me feel less distressed. Paragraphs 5, 55 and 192 of The National Framework explain that you are under a duty to provide a care package which meet my ‘assessed health and associated social care needs’. As outlined in my Care Plan, my needs include a need for a known carer to help me cope with my distress and anxiety when I am in unfamiliar settings such as hospitals. Without a carer my social and emotional needs as outlined in my Care Plan are not met.”

**‘My local authority said they could not fund the care I require when I am in hospital’ or ‘My local authority said my care relates to a medical need and therefore they cannot fund my care’.**

Potential response: There are restrictions which are set out in section 22 of the Care Act 2014 on what types of care a local authority can provide. However, you should ask the local authority to set out the reasons why they think the care relates to a medical need and/or why they think it should be the NHS meeting it. You should then ask the local authority to refer you to NHS Continuing Healthcare if they think you might be eligible. For example you could say “Thank you for your response. I would be grateful if you could help me get the relevant support by referring me for an NHS Continuing Healthcare assessment. As outlined in the Care and Support Statutory Guidance from the Department for Health and Social Care at paragraph 6.80 ‘Where it appears that a person may be eligible for NHS Continuing Healthcare (NHS CHC), local authorities must notify the relevant Clinical Commissioning Group (CCG) [now ICB].’ As my needs are currently unmet, I would be grateful if you would refer me as a matter of urgency.”

If you have already sought support from the NHS and have been told the NHS is not able to provide this support, tell your local authority this. As set out above, your local authority is not prevented from supporting you in respect of a need that the NHS is not able to meet.

If your ICB also says they are not responsible for your care (for example because you are not found to be eligible for NHS Continuing Healthcare) you should not be left without care. You should remind your local authority that they are responsible for assessing and meeting your needs and could ask your ICB and local authority if you would be eligible for a 'joint package of care' which The National Framework (paragraphs 287-293) explains is a care package which is jointly funded by your ICB and local authority.

**'I have emailed/ written to my ICB requesting additional funding to meet my needs and they have not replied to me'.**

Potential response: There are no exact timescales set out in The National Framework for how quickly an ICB should respond to your request for a review of your NHS Continuing Healthcare package. However, the ICB should still respond to your request within a reasonable timeframe (in the context of a hospitalisation 7 days is likely to be a reasonable timeframe). Paragraph 201 of The National Framework states that 'some individuals will require more frequent review in line with clinical judgement and changing needs and paragraph 202 of The National Framework states 'a guiding principle is that the frequency, format and attendance at reviews should be proportionate to the situation in question'. Therefore, if you haven't heard back from your ICB within a reasonable timeframe you could write to them again and say:

"I previously wrote you on [insert date], explaining that my care needs in hospital were not being met and requesting additional funding through my NHS Continuing Healthcare package in order to meet my needs. I have not had a response to this request, which has meant my care needs have continued to go unmet. As outlined in The National Framework at paragraph 202, reviews may need to take place more frequently if a person's needs change. As I outlined in my previous letter, my needs have changed since entering hospital, as I now require [outline your needs and why they have changed as a result of your hospital admission]. When my needs are not met it results in [explain the impact it has, including if it causes you distress or impacts your physical/mental health]. In light of this I would be grateful if you would respond to my request for additional funding for care as a matter of urgency.

If I don't hear back from you within [insert the date by which you wish to hear back] (7 days is likely a reasonable timeframe but a shorter period may be appropriate if your needs are particularly urgent) I will make a formal complaint and may consider taking legal action."

If you still don't hear back from your ICB you could consider making a complaint. The [NHS Constitution](#) sets out your rights and explains that if you make a complaint then you have the right for that complaint to be 'acknowledged within three working days and to be properly investigated'.

**'I have emailed/ written to my local authority requesting funding for additional care and a review of my care and support plan and they have not replied to me'.**

Potential response: There are no specific timeframes set out in the statutory guidance by which a local authority must respond to your request for a review of your needs and care plan. However, the local authority should still respond to your request within a reasonable timeframe and what is reasonable will depend on the urgency of your needs. [The Care and Support Statutory Guidance](#) from the Department of Health and Social Care explains at paragraph 13.20 that local authorities should provide you with information about 'what happens after a request is made, and the timescales involved in the process'. The Guidance further explains at paragraph 13.34 that reviews 'should be performed as quickly as is reasonably practicable' and that 'it is expected that in most cases the revision of the plan should be completed in a timely manner proportionate to the needs to be met'.

If you have written to your local authority and they have not responded to you, a potential response would be: "I previously wrote you on [insert date], explaining that my care needs were not being met and requesting a review of my care and support plan. I have not heard back from you, which means my care needs continue to go unmet. As outlined in the Care and Support Statutory Guidance from the Department of Health and Social Care (paragraph 13.34) reviews of care and support plans should take place 'as quickly as is reasonably practicable'.

Furthermore, this Guidance sets out at paragraph 13.20 that people should be provided with information about ‘what happens after a request is made, and the timescales involved in the process.’ To date, I have not received any information about the timescales involved in getting my care and support plan reviewed and am therefore requesting this information as a matter of urgency. Further, as set out in my previous correspondence, my care needs include [list some of your care needs] and when these needs are not met it results in [explain the impact it has, including if it causes you distress or impacts your physical/mental health]. Consequently, I would be grateful if you could respond to me as soon as possible and arrange for a review of my care and support plan at your earliest convenience. If I don’t hear from you by [insert date you want to hear back by] I will consider taking legal action.”