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How To Get The NHS To Pay For Care

The essential guide
to NHS Continuing
Healthcare
assessments



- Cut through the confusion
- Discover what's right - and what's not
- Understand what to do and say in an assessment

Angela Sherman

Edition 2.2.2 July 2018

This easy-to-follow guide helps you:

- understand what NHS Continuing Healthcare is
- apply for NHS Continuing Care funding
- understand the assessment process
- know what to do and say in assessments
- clarify what's right and what's not
- avoid the pitfalls
- know what to do when things go wrong

The prospect of reading through this guide may feel daunting – but take heart. It's written specifically to help you step by step – starting with the basics and taking you right through the Continuing Healthcare assessment process. It's easy to follow.

* * * * *

What people say about this guide:

This book is going to be a useful tool, and I feel empowered reading it. What you've done is so helpful. I was feeling 'over my head' but now I'm going to go for it.

Rosemary Henderson

'How To Get The NHS To Pay For Care' is a model of clarity compared to the 'official' publications, and a great blueprint to help in a potential battle for funding.

Michael Duncan

The books have proved to be invaluable – and your advice most helpful. I used it as a basis for further discussion with social services, and it resulted in a positive response.

Paul McFarlane

Thank you for your continued support in my mission to see my friend receive the Continuing Care assessment I have been pursuing for many months. At last I can report some good news. Following a decision making meeting this morning, I am informed that from today the NHS will now fund her care. Hopefully our case goes to show that it pays to persevere. My mission to get a Continuing Care assessment has taken a great deal of complaining, letter writing and research on the internet. For me it has been a real eye opener and engaged me in a time consuming yet learning experience. For my friend, it means she is at last being treated with the dignity and respect she deserves. Thank you for your support, without which I doubt if I would have had the confidence to get this far.

John, Southend on Sea

My mother has now got through the Checklist with 5 Bs, so we are onto the next stage. It is true what you say in your guide about letting the assessors know you are informed – I told them I had done my research and been on the NHS website, and I even produced the same Checklist as the assessor had. It really was quite straightforward. I had prepared myself for continually pointing out it was ‘health’ needs and not ‘social’ needs, but I didn’t need to. I’ll keep you informed, and once again many thanks for all your support and information – couldn’t have done it without that.”

Carole, Sussex

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The legal bit

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From the author, Angela Sherman

Based in Buckinghamshire, Angela Sherman is a writer and speaker who is passionate about the rights of older people in care...



“Thank you for purchasing this guide. I drafted the original edition back in 2010, not long after my parents had died, and I’ve updated it regularly since. I went through an exhausting battle with the NHS on my parents’ behalf to access full NHS Continuing Healthcare funding. I succeeded, but it took three and a half years and I was shocked at the tactics used by the NHS to try to deny my parents this funding.

“When I started looking at Continuing Healthcare in 2005, I knew nothing about the care system or NHS funding, and I had to learn everything from scratch. I didn’t know anyone with specialist knowledge who could help me through the assessment process, there was very little practical information on the internet about it at the time. I found the whole thing daunting and distressing. If I’d known then what I know now, it would have been much easier.

“My elation at finally securing Continuing Healthcare for my parents was mixed with great anger. Like so many people, I had to jump through ridiculous hoops to access the funding – and to counter the illegal decisions by the NHS in denying care that should have been free of charge all along. That’s why I wrote this guide and set up Care To Be Different – to help other families in the same situation and to provide a practical route-map through the assessment process.

“I hope you’ll find it helpful. All feedback is very welcome. Do have a look at our website and blog, too, for further useful information.”

Who is this guide for?

If you have:

- a relative in hospital or at home who will soon need full time care because of health needs
- a relative who is already receiving full time care for health needs – in a care home or in their own home – *and* paying care fees
- friends/contacts in this situation who may be unaware of the NHS funding their own relatives are entitled to

...this guide is for you.

It will also help you if you are a professional adviser, such as a solicitor or financial adviser, helping clients with care fees matters.

Is NHS Continuing Healthcare the same across the UK?

No.

This guide deals primarily with the care funding system in England.

NHS funding for full time care is called NHS Continuing Healthcare. The guidelines surrounding this funding in England are in a document called the [National Framework for NHS Continuing Healthcare and NHS Funded Nursing Care](#), and this first was introduced in October 2007. The latest version was published in November 2012. (This link takes you to the Gov.uk website.)

It was introduced initially in an attempt to streamline NHS funding assessments and eligibility criteria across England, to create national eligibility criteria and to eliminate the postcode lottery for care. However, it has done no such thing. NHS assessors interpret the guidelines subjectively, often ignoring what's actually written in black and white. Given the extent of ongoing complaints from families about the Continuing Healthcare assessment and appeal process, it appears to have had little effect in reducing this postcode lottery. Since the 'reorganisation' of the NHS in 2013 and cuts to health and social care budgets, things have got worse, and families need to be aware of what they will come up against in assessments and what they can do in response.

The National Framework referred to in this guide applies to **England**.

Wales has its own National Framework, which is similar to the English one, although there are differences in the eligibility criteria.

However, much of the general advice you'll find on these pages will still be helpful if you're in Wales – but make sure you also read the guidelines specific to Wales. Read more here:

<http://www.wales.nhs.uk/continuingnhshealthcare>.

Although NHS Continuing Healthcare funding is available in **Northern Ireland**, there is no National Framework. Each health and social care board sets its own rules about funding. Although this guide may be useful in terms of showing you how to argue your case, there is no formal framework and the eligibility criteria will be different.

Similarly, in **Scotland** although there is guidance from the NHS in Scotland about NHS Continuing Healthcare, the legal framework is different and is not covered in this guide. Also, the Scottish government indicated in 2014 that from April 2015 NHS Continuing Healthcare funding would only be available in NHS establishments and not in private care homes. However, it remains to be seen if, and how, that might actually happen. This would of course be a devastating blow to people needing long term nursing care should that change actually be made.

Many elderly people needing care are, unfortunately, not in a position to find out for themselves what funding they're entitled to or to fight for it, and very often neither they nor their families will have even been told that NHS funding is available.

In most instances a family member or friend will act on behalf of an elderly person in care. You may be acting on behalf of a parent or other relative. You may be acting in a professional capacity as a solicitor, financial adviser or healthcare practitioner on behalf of a client or patient, and/or you may hold a power or attorney for that person. This guide addresses you, the representative, directly –

rather than addressing the elderly person needing care, and refers to the person needing care as ‘your relative’.

If you **are** the person needing care, this guide will be equally relevant and useful for you. We’re very aware that, in common with many other elderly people, you may often experience people talking ‘over’ you and talking ‘about’ you – instead of talking with you. That is certainly not our aim here. We just know that most people in care need someone to act for them, and so we hope you appreciate why we’ve written it this way.

How to use this guide

The information in this guide steers you through the complexities of NHS Continuing Healthcare funding for full time care and helps you make sense of it. It includes the things that the NHS and your local authority probably haven't told you – and may not ever tell you! – and it shows you what you need to do to give yourself the best chance of securing the NHS care funding your relative is entitled to.

NHS Continuing Healthcare funding covers **all** the fees charged for full time care in a care home or for full time care at home. This funding is often wrongly denied to people by illegal means-testing. By reading this guide you'll learn how to apply for and pursue this funding – and challenge the care authorities when funding is denied.

Although the content focuses predominantly on elderly people needing full time care, the information about funding and care provision is, in many instances, also relevant to younger people over 18 needing full time care. Bear in mind, though, that our specific focus here is older people.

The information on each page of this guide has been created through careful research, together with the personal experience of both the author and also other families with elderly relatives in care.

The guide looks at NHS funding for full time care and nursing care, rather than at community care or social care services. It's important to bear in mind, though, that if you're told you need community or social care (which is means-tested) you may in fact need NHS care, which is free at the point of use. This guide will help you understand the difference.

It's helpful to read the chapters in order. However, we appreciate you may want to dip in and out at random. For that reason, and to help you understand each page as fully as possible, you may find that some of the information is repeated in more than one section.

Everyone's circumstances are different. Following the steps in this guide does not always guarantee you success in securing fully-funded NHS care for your relative. However, it certainly gives you a much better start – and a much better chance of winning. It also makes things much easier for you – and saves you a huge amount of time and research. Plus, it will give you the peace of mind that you're doing the best you can for your relative.

As you go through the chapters in this guide, you'll understand much more and you'll know exactly what to do.

You'll uncover specific actions you can take in different situations, plus clear answers to typical questions about Continuing Healthcare funding. You'll also discover some of the *misinformation* you may have received from the NHS and/or your relative's local authority.

It's your companion every step of the way, to encourage you and spur you on and help you achieve a fair and just outcome for your relative. Author, Angela Sherman, has 'been there and done it' – not only herself but also by helping other families through the process. She understands how difficult it can be and the obstacles you may face.

Acting on behalf of someone in care can take a lot of physical and emotional energy and requires stamina. That's why it's vital to look after yourself, too. Get enough sleep, drink lots of water, exercise when you can, eat healthy, nutritious food and make some time for you where you can.

Glossary

These are some of the terms, abbreviations and acronyms you'll find, not just in this guide, but also in other information you may read about care and care fees.

*More information on some of the new organisations mentioned below can be found in subsequent sections of this guide:

Capacity	Mental capacity – the ability of someone to make a decision for themselves about a particular issue
CHC	NHS Continuing Healthcare (also known as 'Continuing Care' and 'fully-funded NHS care')
Checklist	The Checklist – the initial screening assessment used to decide whether someone 'warrants' a full assessment for NHS Continuing Healthcare
CCG*	Clinical Commissioning Group – group of GP practices plus other practitioners and lay people. Accountable to the NHS Commissioning Board (NHSCB).
CQC	Care Quality Commission – quality inspectorate across health and social care
DDA	formerly the Disability Discrimination Act (now the Equality Act)
DoH	Department of Health

DST	Decision Support Tool – the document used to record all the notes in a full assessment for NHS Continuing Healthcare
EA	Equality Act 2010 (formerly the Disability Discrimination Act)
EMI	Elderly Mentally Infirm (often used to describe care homes that look after people with dementia)
EPA	Enduring Power of Attorney
FNC	Funded Nursing Care (also known as ‘Registered Nursing Care Contribution’ or ‘NHS-funded nursing care’ or ‘free NHS care’ – just to confuse matters)
GP	General Practitioner
FTPT	Fast Track Pathway Tool – the document used to decide Continuing Healthcare eligibility for someone who is rapidly deteriorating or in ‘terminal decline’
HW*	Local HealthWatch – the local level consumer ‘voice’ in health and social care; replaces previous Local Involvement Networks (LINKs)
HWE*	HealthWatch England – national level; supports local HealthWatch bodies, looks into complaints and examines the performance of health service providers
HWB*	Health and Wellbeing Board – within local authorities; encourages greater integration of health and social care

IRP	Independent Review Panel – special appeal hearings to review eligibility decisions for Continuing Care once the local CCG appeal process has been exhausted
LA	Local Authority (local Council) – often referred to informally in a care context as ‘Social Services’
LPA	Lasting Power of Attorney
MCA	Mental Capacity Assessment
MHA	Mental Health Act
Monitor*	New economic regulator for all NHS-funded services in England
NHSCB*	NHS Commissioning Board; oversees CCGs and also takes on responsibilities of previous Strategic Health Authorities (SHAs); also known as the National Commissioning Board
NHSE	NHS England; oversees the budget, planning, delivery and day-to-day operation of the NHS in England.
NICE	National Institute for Health and Care Excellence (formerly the National Institute for Health and Clinical Excellence)
PCT**	formerly Primary Care Trusts – replaced by CCGs on 1 st April 2013

RNCC Registered Nursing Care Contribution (also known as ‘NHS-funded nursing care’ or ‘free NHS care’ or ‘Funded Nursing Care’ or ‘FNC’)

Section 2 Form issued by an NHS hospital, transferring responsibility for care to the local authority

Section 47 A local authority financial assessment (more commonly known as means testing)

Self-funding The inappropriate term given by local authorities and the NHS to people in care who have been told to pay their own care fees – often without any basis

SHA** formerly Strategic Health Authority (regional body); abolished from 1st April 2013 and replaced loosely by the NHS Commissioning Board (NHSCB)

* Established in the new Health and Social Care Act 2012 for England (the ‘NHS reforms’)

** abolished as part of the rollout of the new Health and Social Care Act 2012 in England

A personal view of the care system for older people in the UK

by Angela Sherman, Director, Care To Be Different

The elderly care 'system' in the UK can be complex and often confusing – not just for families but also for the people who work within the system. This is not helped by the new NHS reforms in England and the restructuring of the various organisations that make up health and social care.

As someone with a vulnerable elderly relative you need to know what to do and who to talk to in order to secure the best care and support for your relative, whether they're at home, in hospital, in a care home or somewhere else. But when you don't know what you don't know, it can feel like you're fighting in the dark much of the time.

It can also feel daunting when you're thrown into the position of having to deal with the various 'authorities' that make up the care system. You may find that the information you're given by your local authority and/or the NHS is less than clear, and many families also discover, over time, that what they've been told is actually incorrect. There is often very little clarity or transparency.

The NHS: free at the point of use?

Nursing care in the UK is free at the point of use. Or is it? The principle is embodied in the 1946 National Health Service Act and it's what gives the NHS its strength. It doesn't matter how old a person is, how long an elderly person might need care for or whether they receive that care at home, in a care home, a hospice or hospital, nursing care is free at the point of use. It's as simple as that.

However, every year thousands of elderly people in the UK have their needs wrongly defined as ‘social’ needs, instead of ‘healthcare’ needs, and, as a result, are forced to pay for nursing care. Presumably it stems from the NHS’s desire to protect budgets. However, it’s illegal. It doesn’t matter how the care is described, e.g. ‘care in a care home’ or ‘long term care’, if it’s healthcare, it is the responsibility of the state to provide it.

[The main NHS.uk website](#) states that:

“The NHS was born out of a long-held ideal that good healthcare should be available to all, regardless of wealth, a principle that remains at its core. With the exception of some charges, such as prescriptions and optical and dental services, the NHS remains free at the point of use for anyone who is a UK resident. That is currently more than 64.1m people.... It covers everything from... routine screenings... and treatments for long-term conditions to transplants, emergency treatment, and end-of-life care.”

The reality is, though, that elderly people in need of nursing care are often wrongly told they will be means-tested for ‘social’ care (instead of health care). They are routinely told they will have to sell their homes to pay for it. Someone who is vulnerable, and this includes the family of that person in this context, is not usually in a position to challenge that decision – because they’re likely to trust what they’re being told.

We have all become conditioned to believe that when you get older you have to pay for care. But where does that come from? One easy answer: the health and social care authorities who seem keen to protect their budgets and who, as part of that, provide flawed – and often downright misleading – information to people needing care. Sadly the same thing is often perpetuated in the press. When did you

last hear a news report about care fees mention NHS Continuing Healthcare funding?

Elderly people needing full time care for health reasons in the UK are just as entitled to free NHS care as everyone else.

Until this wider issue is resolved, families are likely to have to continue to jump through many hoops to access care funding for elderly relatives.

What makes it worse is that many NHS and local authority staff do not seem to have been properly trained in the rules surrounding NHS Continuing Healthcare. It seems to be up to patients and their families to pick up on mistakes in procedure and to challenge them.

Denial of NHS care

Lack of training is one thing. However, our blog and many other online forums contain many examples of families on the receiving end of what they feel is deliberate misinformation, intimidation and delaying tactics on the part of some NHS and local authority departments, particularly when it comes to elderly people and full time care.

The NHS and local authorities cannot make up new rules simply because they don't like the law. The law is clear.

Angela Sherman

I: How to navigate the care maze

Who provides care?

The NHS in England has undergone its biggest reorganisation since it came into existence in 1948. The 2010 coalition government's plans to restructure the NHS became law in March 2012 through the Health and Social Care Act 2012. The original Bill had a rough ride, and hundreds of amendments had to be made, but it was passed into law. There has nevertheless been a lot of opposition from many quarters, not least from the medical profession. The new Care Act 2014, covering care and support services (largely to do with social care) has now also come into effect.

If the people on the 'inside' are confused, it doesn't exactly bode well for families on the outside, and with such major reorganisation there are concerns that vulnerable people, especially elderly people, could fall through the cracks. So stay alert to what's happening.

The Dept. of Health guidelines about NHS Continuing Healthcare funding were redrafted at the end of 2012 and came into effect as of 1st April 2013, to coincide with the NHS reforms. We look at these new guidelines in this guide.

You may be aware that, prior to 31st March 2013, it was possible to reclaim care fees in England that had been incorrectly charged in the past. Again, the care fees reclaim deadlines were imposed by the NHS to coincide with the NHS reforms and for the benefit of the new Clinical Commissioning Groups (CCGs) – not for the benefit of the tens of thousands of people who have been wrongly charged. It remains to be seen whether anyone will challenge these deadlines in the courts. The basis on which they were imposed seems seriously questionable – as the organisation that has illegally charged care fees

in the first place has subsequently made the decision to no longer give that money back!

The initial aim of the NHS reforms was stated as a means to cut bureaucracy and abolish layers of regional and local NHS management. Major bodies such as the 152 Primary Care Trusts (PCTs) and the 10 Strategic Health Authorities (SHAs) were abolished and replaced with lots of new bodies – far more in number than the ones being abolished. That in itself calls into question whether the amount of management resource really has been reduced.

This is how care is provided:

NHS – Health Authority – Clinical Commissioning Groups

(CCG): The NHS has a statutory responsibility for providing services to meet health needs, including both general and specialist nursing care. These services include GP practices, dentists, district nurses, NHS hospitals (also called NHS Trusts or NHS Foundation Trusts), and nursing care in all care homes and for people in their own homes. Long term care funding from the NHS is coordinated through the Continuing Healthcare Department at the CCG.

Local authority – Local council – Social Services:

The local authority assesses people's needs for 'community' or 'social' care. Whenever care becomes a local authority/Social Services responsibility, the person receiving it will be means tested. Local authorities also provide means tested social care in care homes. If someone is means-tested and it's clear that person cannot afford to pay for care, the local authority will cover the cost (although a family member may be asked to 'top up' the fees if those fees are above what the local authority is prepared to pay – but keep in mind that top-up fees are not always due:

<http://www.caretobedifferent.co.uk/care-home-top-up-fees/>). Social Services/local authorities do not (and should not) provide or charge individuals for registered nursing care.

Sometimes the NHS will ask Social Services to deliver a particular package of care for someone (either in a care home or in that person's own home), but in such an event the NHS is still responsible for paying for it.

Generally speaking, **social** care is provided by Social Services (local authority), and **health care and nursing care** is provided by the NHS. But this is where the problems start. Read on...

Health vs. social care – what’s the difference and why does it matter?

To answer this question it’s probably easiest to describe ‘social’ care needs: These are things like needing help with washing, dressing and feeding, getting to the toilet and getting around, as many elderly people do. These things are often termed the ‘activities of daily living’ (ADLs). However, in many cases it’s fair to say that you wouldn’t need this so-called ‘social’ care if you didn’t have underlying *health* needs in the first place.

Many elderly people who need care are told that they have ‘social’ needs (means-tested care), not ‘health’ needs (NHS care – free of charge), and it’s this distinction that often leads to them being wrongly charged. If your relative is in care because of health needs, they may be receiving some kind of nursing care – **and nursing care is free at the point of use**. However, the NHS will often say that it’s ‘not enough’ nursing care to warrant the NHS providing all of that that care free of charge.

And so the NHS may attempt incorrectly to redefine a health need as a social need as it did in the landmark Coughlan court case. See next section. This is one of the main reasons why people end up paying for long term care, when it should be provided free of charge through NHS Continuing Healthcare.

What do the NHS Continuing Healthcare guidelines say?

Let’s look at the National Framework, page 50 paragraph 2.1, 2.2 and 2.3. These guidelines attempt to clarify the difference between and healthcare need and a social care need:

“2.1 Whilst there is not a legal definition of a healthcare need (in the context of NHS continuing healthcare), in general terms it can be said

that such a 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).

2.2 In general terms (not a legal definition) it can be said that a social care need is 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 (in some circumstances) accessing a care home or other supported accommodation.

2.3 Social care needs are directly related to the type of welfare services that LAs have a duty or power to provide. These include, but are not limited to: social work services; advice; support; practical assistance in the home; assistance with equipment and home adaptations; visiting and sitting services; provision of meals; facilities for occupational, social, cultural and recreational activities outside the home; assistance to take advantage of educational facilities; and assistance in finding accommodation (e.g. a care home), etc....”

It's clear that someone who needs full time nursing care does not simply need social care services from a local authority. In addition, it is illegal for a local authority to take on responsibility for providing care to someone who should be receiving care from the NHS.

Again, see the next section about the Coughlan case, which concluded that:

Unless nursing care services are “**merely incidental** or ancillary to the provision of accommodation... and of a nature that an authority whose primary responsibility is to provide social services can be

expected to provide”, a person’s care is the responsibility of the NHS – and it should be fully funded by the NHS.

It means that any attempt by a local authority to take responsibility for such care (and certainly if a local authority starts charging top-up fees for such care), is likely to be illegal.

And yet thousands of people with significant healthcare and nursing care needs are currently paying for every penny of their care – because the NHS has passed responsibility for care to the local authority, which in turn puts the person needing care through means testing.

No one in the NHS or Social Services can brush aside the rules just because they haven’t clarified them for themselves or don’t believe they’re relevant.

Double charging for care

Many people assume that what they’re told by the NHS or by their local authority in terms of having to pay for care is right. But where the line is drawn between health and social needs can make the difference between someone being able to hold on to all their hard-earned money and assets and potentially losing everything they own.

If you’re looking at information from various sources relating to long term care funding, including on charity websites, you’ll find it plentiful. However, always keep in mind that much of that information won’t make the point strongly enough that, when someone needs care, any assessment should first and foremost be about **health** needs. Means testing by Social Services (local authority) for ‘social’ care is strictly secondary.

An NHS assessment of your relative's health needs may indicate that the NHS is responsible for providing care through NHS Continuing Healthcare. If that's the case, the care will **all** be free of charge, including 100% of the costs of being in a care home or receiving care at home – including any social care required. That's why it's vital that proper assessments are carried out and in a timely manner.

Because the NHS will not want to foot the bill for long term care, it often seems to do everything it can to keep the responsibility for payment of care fees at Social Services' door. If the NHS **does** succeed in defining your relative's needs as social needs, Social Services will do a financial assessment of your relative. It means that if your relative has savings over the current capital and savings threshold for local authority care, you'll be told they have to pay for care.

What all this means, though, is that elderly people with health needs are effectively being double-charged for care: They've already paid for NHS care all their life through taxation and now they're paying all over again.

Be vigilant

With any care matters, if your first port of call for help and advice is often the local authority or a hospital social worker, you may find that paying care fees is the first thing they mention and that they're interested only in how much money your relative has. **These questions are unlawful at this point – because at this point no one has properly evaluated your relative's health and care needs to see who is actually responsible for paying for care.**

Receiving help and accurate advice should have nothing to do with how much money your relative has. It's a good move to remind the

local authority representative of that. Before any decisions are made about care funding for someone with health needs, an assessment for NHS Continuing Healthcare should be carried out. (Read more in later sections of this guide.) You may observe how people in ‘authority’ start backtracking when you mention the guidelines – it tends to encourage them to do things properly. Also, it never hurts to continually remind the local authority and the NHS of the judgment in the Coughlan case. (See next section on this.)

In all of this, the key thing to remember is that your relative should *first* be assessed for fully-funded NHS care (NHS Continuing Healthcare) without any financial means testing from Social Services/the local authority.

Whether your relative is in hospital and needing long term care, in their own home or already in a care home, the first question anyone should ask you is about your relative’s **health** needs. Just because someone says at this stage that your relative needs social care, not health care, doesn’t mean they’re right!

Stay alert. Initial decisions about your relative’s care are likely to be based on budgets and financial agendas – not on care needs.

The Coughlan case – and how it clarified the law regarding NHS Continuing Healthcare

This section on the Coughlan case and the next one on the Grogan case are useful background information, and we've included them here because of their importance in setting the legal foundation for care funding decisions. It's worth reading them for that reason – and because you will almost certainly come across them if you're pursuing NHS funding for a relative.

The Coughlan case

In the 1970s Pamela Coughlan was paralysed after a road accident and she needed full-time care. She had severe physical disabilities including partial paralysis of her respiratory tract.

At the same time, however, she could still speak coherently and with mental clarity, use an electric wheelchair by herself, use a computer with voice technology, and eat and drink with some assistance.

Her care was financed by the NHS until, in the 1990s, her local authority (the East Devon Health Authority) transferred responsibility for her care to Social Services. By reclassifying her needs as 'social' care rather than 'health' care, this meant she would now be means tested and have to pay for her own long term care.

She pursued a case against the NHS to secure NHS Continuing Healthcare, fighting it in the High Court. It took two years and, in 1999 after an unsuccessful appeal by the then Labour government, she finally won a landmark case in the Court of Appeal. (The judgment applies to England and Wales).

Unlawful actions

The Court agreed that the actions of the local authority had been unfair and that the NHS had not followed its own guidance. It stated

that the NHS had reneged on its promise to provide long-term care, used inconsistent eligibility criteria and had consequently made unlawful decisions.

Nursing care responsibility

The key question was whether nursing care for a chronically ill patient can lawfully be provided by the local authority as ‘social’ care (means-tested) or whether it must be provided free of charge in law by the NHS.

In court the judge ruled that both general and specialist nursing care were the sole responsibility of the NHS. However, the Court of Appeal subsequently found that the local authority *can* provide some nursing care, but only when that is not the primary health need.

This principle is now known as the ‘Primary Health Need Approach’ and it is applied in all assessments for NHS Continuing Healthcare. More on that later.

In Pamela Coughlan’s case, the Court of Appeal ruled that her nursing care *was* the responsibility of the NHS, not the local authority. **The Court also ruled that care for people with ‘stable yet chronic conditions’ (not just acute conditions) can also be the responsibility of the NHS.**

The Coughlan ‘test’

The ruling also indicated that anyone with needs the same as or greater than Pamela Coughlan should be eligible for NHS Continuing Healthcare. The measure of her health needs became known as the ‘Coughlan Test’.

The case clarified the law regarding NHS Continuing Healthcare. The Court of Appeal stated that...

“...where the primary need is a health need, then the responsibility is that of the NHS, even when the individual has been placed in a home by a local authority.”

The judgment also concluded that the ‘vast majority’ of people in nursing homes should have their care fees NHS funded, and that only if someone’s health care needs are ‘incidental’ to their overall care needs should the responsibility be passed to Social Services.

Despite the Coughlan case, tens of thousands of elderly people with health needs as their primary needs are still being forced to pay for their own care.

When the National Framework for NHS Continuing Healthcare was first introduced back in 2007, it aimed to streamline care eligibility criteria across England. However, there is a legal argument that suggests if Pamela Coughlan’s were measured against this National Framework, she would be found ineligible for NHS funding!

This would indicate that the National Framework itself may be illegal – because the National Framework does not replace case law.

The Grogan case

In 2006, Maureen Grogan’s family successfully challenged Bexley NHS Trust in the High Court about their decision not to provide Mrs Grogan with fully-funded NHS care. This has become another important case in NHS Continuing Healthcare and Funded Nursing Care.

(Funded Nursing Care is covered in a later section of this guide.)

At the time Mrs Grogan, 65, was chronically ill with multiple sclerosis and additional health needs, including dependent oedema and the associated risk of ulcers. She had nil mobility, was totally dependent and also experienced cognitive impairment. She was in a nursing home and she had already had to sell her house to pay for care.

The judgment in her case at the High Court showed that the criteria used by the NHS in their care funding decision had been “fatally flawed”. The final judgment also found that the local NHS Trust (Bexley) had moved the goalposts in terms of defining her level of need. The judge ruled that she should not have had to pay for her own care and, instead, the NHS had a legal duty to pay for all of it. Like the Coughlan case, the Grogan Case has given families who are pursuing NHS funding further clout in their legal argument.

Challenging the NHS can be a hard fight, and it helps enormously to be able to refer to and take courage from people who have already succeeded.

The NHS had assessed her three times as ‘ineligible’ for NHS Continuing Healthcare – even though the care assessments showed she had substantial health needs. She was receiving only the (then)

top band of Funded Nursing Care (FNC) payments – also known as Registered Nursing Care Contribution (RNCC).

The Grogan Case relied heavily on the legal argument that came out of the Coughlan case, and it was found that the NHS had not followed the Coughlan test in its decision-making process.

Hidden agendas – do the NHS and local authority work together?

Ongoing care for a vulnerable elderly person is supposed to be a partnership approach between the local authority (usually Social Services) and the NHS (usually the Continuing Healthcare Department at your local CCG).

The Social Services team will know the people in the NHS Continuing Healthcare team, and vice versa. Indeed, government guidance states that they should work together in partnership, and one of the aims of the new legislation in England has been to get them working together more effectively.

However, this does not mean the NHS can simply pass care funding responsibilities over to Social Services (the local authority) without foundation.

The NHS's duty to provide free care seems to be open to interpretation by the various authorities involved – and those authorities often do little to dispel the myth that, if you're elderly and you need care, you have to pay for it. It's no wonder that it's difficult for families to know where the responsibility really lies.

The NHS seems happy to fund treatment for people where an acute or short-term need is apparent, but when it comes to chronic/long term care – and elderly people – it doesn't seem quite as keen. Indeed, online forums show that many elderly people who are terminally ill still struggle to access the NHS care that is available free of charge to the rest of the population. They have to undergo convoluted assessments and be measured against punitive eligibility criteria to access care that should be free to all at the point of use.

Find potential allies

If you attend health needs assessments as your relative's representative and advocate, it's always a good idea to gauge what the relationship seems to be like between Social Services and the NHS – and who your potential allies could be. If a representative from Social Services becomes aware at any point that your relative does indeed have **health** needs, that Social Services employee should point this out to the NHS. Remember, though, that each party has an agenda. That agenda may not be obvious, but will almost certainly be to do with money.

Unfortunately, your relative can become a pawn in the middle, being batted to and fro between budget holders reluctant to part with any of that money.

The whole system can seem ludicrous. Hospitals want to get elderly people out of hospital beds as soon as possible and often accuse them of 'bed-blocking'. The NHS is responsible for assessing eligibility for fully-funded NHS care – and yet it also holds the purse strings. A care home or care provider wants to look good and so may present an overly positive impression of your relative's health, which means the severity of care needs may not be properly taken into account in assessments. Plus, care homes earn more money when a resident is paying their own fees – and so it's not necessarily in the home's financial interest to help a resident secure NHS Continuing Healthcare or local authority funding. And the local authority knows that if your relative has savings, then its budgets are safe and your relative will probably pay. It's not a good situation at all.

Many people assume that a GP will be able to help – as a kind of advocate in the process. It's worth mentioning here though, as a general statement, that many GPs are not familiar with the law or the guidelines surrounding Continuing Healthcare funding, and so you

cannot necessarily rely on a GP to help you with information in this respect. In that sense it's not exactly encouraging for families that the new the NHS reforms have put most of the NHS budget – and the responsibility for commissioning services – into the hands of GPs. As before, families will almost certainly have to fight hard and be the ones who lead their relative's GP into understanding how things work. However, the more GPs who are made aware of these things – by families fighting for care – the better.

This may paint a rather bleak picture, but it's better to be aware of these things than not – and there are many positive steps you can take to fight your relative's corner.

NHS Reforms in England – and what they mean for you

After this section we'll move on to the practical tips and guidance you need about care fees and applying for NHS Continuing Healthcare funding.

Before that though it's worth explaining a bit more about the NHS reforms in England, how they affect the structure of the health and social care system and how they affect the application and appeal process for NHS Continuing Healthcare.

Don't worry about taking in all the information on all the new structures. The two key ones to remember are:

- **the Clinical Commissioning Groups (CCGs)**
- **the NHS Commissioning Board (NHSCB)**

The 2010 coalition government, the author of the reforms, stated at the time that the government *“upholds the values and principles of the NHS: of a comprehensive service, available to all, free at the point of use and based on clinical need, not the ability to pay”*.

It stated that patients should have access to the information they want and have increased control over their own care records (this would include care plans), to choose a GP at any GP practice, to have *“choice in care for long term conditions”*. In end-of-life care people should have the support they need and the reforms should *“reinforce local accountability”* and ensure that *“we do not exclude outcomes for key groups...such as...older people and mental health”*.

Further... *“money will follow the patient through transparent, comprehensive and stable payment systems... and support patient choice”*,

and a new structure will “*tackle inequalities in access to healthcare*”, achieve “*fairness for everyone*” and “*break down the barriers between health and social care funding*”.

It also stated: “*We are committed to promoting equality and will implement the ban on age discrimination in NHS services and social care*”, and that the new NHS Commissioning Board will have an explicit duty to address inequalities.

The government also reaffirmed its commitment to “*uphold the NHS Constitution*”.

All the above points are important to remember and useful to argue if you find yourself denied NHS Continuing Care funding.

The government was forced to make changes to its original reforms, on account of serious concerns from many quarters about the degree of private sector power and the lack of care quality safeguards, and there are still concerns from many health professionals.

Some of the key features of new legislation include:

- There is now less emphasis on the NHS’s responsibility to ‘provide’ care; instead, the language has changed from ‘provide’ to ‘promote’. What this means in practice is that the NHS can now use private companies to provide care. This includes at local level, via CCGs. There is likely to be much more private sector involvement.
- Despite the focus on bringing health and social care together, there is still a divide in the overall structure – and there is a very important divide when it comes to NHS Continuing Healthcare funding.

- There are now over 240 CCGs – far more in number than the previous PCTs – which suggests more complexity and a system that is potentially more costly to manage than before, at least in the short to medium term.
- It's the local CCGs who are now handling the NHS Continuing Healthcare assessment and review process. (Exception: Continuing Healthcare for prisoners and military personnel is handled by the NHS Commissioning Board.)
- Independent Review Panel appeals against local decisions about NHS Continuing Healthcare are now handled by the NHS Commissioning Board (effectively NHS England) - instead of the former Strategic Health Authorities.

Let's look at the various bodies within the structure, old and new, at what their purpose is. Don't worry if this all sounds very complex and confusing at the moment. Following the clear steps in the rest of this guide will stand you in good stead when it comes to applying for NHS Continuing Healthcare funding:

At national level...

Department of Health (DoH)

This is now smaller and more strategic, in theory focusing on tackling inequalities and reforming adult social care.

NHS Commissioning Board (NHSCB)

Also known as the National Commissioning Board. This essentially replaces the Strategic Health Authorities and is accountable to the Secretary of State. It is a statutory body and must draw on specialist expertise, support and advice from people with a broad range of professional and clinical expertise, such as from clinical 'senates' or 'networks' which bring together experts and professionals from right across health and social care. The NHSCB oversees the CCGs and provides advice and guidance to CCGs. Its remit involves placing an emphasis on training and education. It must involve patients, carers and the public via local HealthWatch bodies. (The NHSCB handles the Continuing Healthcare assessment process for prisoners and military personnel. CCGs handle all other cases.)

Care Quality Commission (CQC)

This continues as the care quality inspector for health and social care (although its performance in inspecting care providers seems woefully inadequate). It is no longer responsible for assessing NHS commissioners (now the GPs); this will now be done by the NHSCB. The whole focus of the CQC is now on registering and regulating care providers. But will this simply be more box ticking? It issues licences to adult social care providers and carries out inspections – but it seems these inspections may only be in response to information it receives about a particular provider through a

CCG, a local HealthWatch body or through HealthWatch England. The CQC's response to concerns about care hasn't been good in the past. Patient feedback can be sent to the CQC via a CCG – and there also seems nothing in the reforms to stop patients or families reporting something directly to the CQC.

HealthWatch England (HWE)

This supports local HealthWatch bodies (the consumer voice) and acts as the consumer 'champion'. It's a statutory committee of the CQC and represents people at a national level who use health services. It advises CQC of specific services to review.

Monitor

Monitor is the new economic regulator for all NHS funded services. Its remit is to promote choice and competition. It provides licences to all providers of NHS healthcare services, holds a register of these fee-paying licence holders and it is supposed to act to prevent competitive behaviour (e.g. cutting costs) that is not in the interests of patients. It works with the NHSCB in looking at choice and competition in particular services, at inequalities, access to care and outcomes. It oversees all NHS Foundation Trusts until 2016. It must involve patients, carers and the public via local HealthWatch bodies (see below).

NHS England

NHS England oversees the budget, planning, delivery and day-to-day operation of the NHS in England. Its stated aims are to "*improve transparency*" and "*improve health outcomes for people in England*". It's worth remembering that if you need to take your funding appeal to a regional level. Once you have

exhausted the ‘local level’ appeals process, you’ll need to contact NHS England to arrange an Independent Review Panel hearing.

Public Health England (PHE)

This new national body oversees the whole public health system and is accountable to the Secretary of State.

National Institute For Health and Care Excellence (NICE)

Formerly the National Institute For Health and Clinical Excellence, this stays mostly the same as a public body recommending medicines, treatments and procedures, but it now also includes social care.

Health and Social Care Information Centre (HSCIS)

This is a new central point for information collected from the NHS and from social care organisations. It publishes a code of practice for health and social care bodies.

NHS Trust Development Authority (NHSTDA)

This oversees and governs NHS Trusts.

Health Education England (HEE)

This is a special new health authority with a remit to promote education and training, authorise and support Local Education and Training Boards (LETBs) and in so doing handle the current education and training responsibilities of the previous Strategic Health Authorities.

At regional level...

NHS Commissioning Board (NHSCB)

There are four regional hubs of the NHS Commissioning Board.

At local level...

NHS Commissioning Board (NHSCB)

Also known as the National Commissioning Board. There are 50 Local Area Teams of the NHS Commissioning Board, each with a director.

NHS Trusts

Many of these are now Foundation Trusts, which means they have more managerial and financial freedom, but they still have to abide by the law. The Secretary of State has the power to abolish NHS Trusts at any time of his/her choosing. The new NHS reforms have also removed the cap on how much income a foundation trust can earn from non-NHS sources.

Clinical Commissioning Groups (CCGs)

Healthcare funds are now largely in the hands of GPs instead of Primary Care Trusts – in the form of over 240 localised CCGs (groups of GP practices), each of which has hospital doctors, social care workers and nurses, plus two lay people involved at board level.

CCGs are statutory bodies and as such have to both enforce and abide by the law. Their remit is to manage budgets and commission (buy in) health and social care services for the local population. This includes NHS Continuing Healthcare

(except for prisoners and military personnel), mental health services, community services and acute services such as hospital care. This means that CCGs are, essentially, motivated by money, something that has caused great concern amongst many individual GPs.

CCGs are responsible for making services available, but not necessarily for providing them. Services can be provided by the private sector, but the CCG still has statutory responsibility. It seems CCGs are under no obligation to ensure a full range of services are available to their catchment population. However, they have to uphold the NHS Constitution and the NHS's three core principles, namely that the NHS:

1. meets the needs of everyone
2. is free at the point of delivery
3. is based on clinical need, not ability to pay

They are subject to scrutiny by local authorities through local HealthWatch Boards. CCGs must involve patients, carers and the public in their decisions via local HealthWatch. In making their decisions, CCGs must also obtain advice from people with a broad range of professional and clinical expertise, they must work closely with Health and Wellbeing Boards and they are accountable to the NHSCB.

GPs

All GP practices have to belong to a CCG.

Local authorities (LA)

These now have ultimate responsibility for public health via Health and Wellbeing Boards, which work alongside Public

Health England. Local authorities and CCGs are tasked with building good relationships between each other, in an attempt to integrate health and social care more effectively.

Health and Wellbeing Boards (HWB)

These work within local authorities to encourage integration between health and social care and the pooling of budgets and to improve the health and wellbeing of local populations.

Boards will include the Director of Adult Social Services, the Director of Children's Services, the Director of Public Health, a representative of each Clinical Commissioning Group, a representative of local HealthWatch plus local councillors.

The Boards must also involve patients, carers and the public via local HealthWatch groups.

Local HealthWatch (LHW)

Commissioned by the local authority – and held to account by the local authority – Local HealthWatch has replaced the former LINKs groups (Local Involvement Networks) and operates across health and social care. It's the point of contact for patients (individuals, community groups, voluntary organisations) and has a representative seat on the local Health and Wellbeing Board.

Postcode lottery

Given the high number of CCGs replacing the much smaller number of PCTs, there is a risk that health care provision will become fragmented, leading to an even greater risk of a postcode lottery of care than before. CCGs handle smaller populations than the previous PCTs and so, looking at it one way, a person eligible for NHS Continuing Healthcare funding could have more of an impact on a local CCG budget, which means that, potentially, there's a higher chance the CCG will be reluctant to provide funding, even though

doing so may be illegal. It means families are wise to be well-informed about the funding process and how to fight for that funding.

This geographical fragmentation would seem to bring with it a greater risk of inequalities in access to services – and this could lead to more public expense as people are forced to launch legal challenges.

An example of this is a GP practice in the south of England that was found guilty of breach of contract after it illegally deregistered from its patient list, for financial reasons, 48 elderly people in a care home.

GP knowledge

GPs are by definition generalists and there is no requirement in the new Health and Social Care Act for specialists to be at the heart of the commissioning process, which seems a little crazy. Many families report that many GPs appear to know little about NHS Continuing Healthcare – or about the complex multidisciplinary assessments required for elderly people in full time care, including attention to things like speech and language therapy, falls prevention or the practical day-to-day care needs of people with central nervous system diseases such as Parkinson's and MS or with neuro muscular conditions.

The health service has a very poor track record in managing progressive and chronic disease and has tended (often wrongly) to farm this out to local authorities who then means test. GP groups now hold the budgets and have huge power in their hands, but may not be skilled in using it in the context of long term care. Most elderly people needing care have complex needs including physical and mental health needs. Lack of understanding and subsequent delays in referral could be catastrophic, and families will, as now, continue to be the ones who have to 'educate' health and social care professionals about their responsibilities and remit. If an elderly

person in care or needing care has no family, there is little hope for proper redress.

Definition of ‘NHS services’

NHS services will continue to be funded by the tax payer, however a lot of power is also being transferred to local authorities and some NHS services are also being transferred to local authorities. This means they may no longer be defined as ‘NHS’ services and therefore they may be means-tested.

Lack of transparency

Alongside the original NHS reforms, a ‘risk register’ was originally drawn up. This is a list of risks and negative consequences that could arise from the implementation of all the changes. However, the 2010 coalition government refused to publish it, despite a legal ruling that it should. The Information Commissioner ruled that the Department of Health breached the Freedom of Information Act by failing to publish it – and it is astonishing that the House of Lords passed the new Health and Social Care Act in March 2012 without having access to this risk register. It’s ironic that, on the one hand, the government wants people to have greater access to information about their care and care records, and yet on the other hand refused to disclose information, even when ordered to.

NHS Continuing Healthcare assessment and review process

Decisions about NHS Continuing Healthcare were previously made by PCTs, and families who wanted to challenge decisions about funding did that through a PCT review process – and, after that, through the (former) Strategic Health Authorities (SHAs), if necessary. Families now have to challenge the CCGs and, if a case needs to go further, take it to the NHS Commissioning Board via NHS England. Indications are that the CCGs are less accountable to the Secretary of State than the PCTs were.

Families continually find they are given incorrect information about NHS Continuing Healthcare assessments, eligibility criteria and appeal procedures – either as a deliberate attempt by the NHS to deny funding or as a result of a woeful lack of training for employees. Any information given now to families by health and social care employees must be questioned even more carefully, as there's no guarantee the people working inside the new 'reformed' health and care system will understand things any more than the general public.

Let's get back to care fees and NHS Continuing Healthcare specifically...

The Care Act 2014 – what you need to know

A further new piece of legislation was passed in 2014: the Care Act. Some elements of the Act came into force from April 2015, and the remainder (Phase 2) was due to come into effect in 2016. Phase 2 includes the much publicised ‘cap’ on social care fees.

However, the current Conservative government has now postponed Phase 2 until April 2020. Many people are now also questioning whether it will actually happen at all.

Nevertheless, there are certain points about the Care Act and NHS Continuing Healthcare that you need to be aware of.

The most important point to be aware of is that the Act does not change the rules about NHS Continuing Healthcare funding – nor does it change the rules about who can receive it.

The new Care Act actually supports NHS Continuing Healthcare by placing a clear duty on the health and social care authorities to carry out proper assessments for NHS Continuing Healthcare, particularly prior to discharging a person from hospital.

The NHS Continuing Healthcare guidelines, case law and eligibility criteria remain the same as before the introduction of the Care Act.

Social care vs. healthcare and nursing care

The Care Act is essentially a social care Act – applying for most part to local authority care, i.e. means tested care.

As we’ve already seen, generally speaking there are two types of care:

- 1 social care: provided by a local authority and means tested
- 2 healthcare/nursing care: provided by the NHS; not means tested.

This distinction is vital. The Care Act deals primarily with social care, i.e. local authority means tested care.

Do not believe anyone who tells you any of the following:

- That the new Care Act abolishes NHS Continuing Healthcare funding. It does not.
- That all care will now be means tested, including NHS Continuing Healthcare. It is not. NHS Continuing Healthcare is not means tested.
- That the new Care Act does away with the above distinction between social care and healthcare funding. It does not.

Self-funders and the Care Act

If you don't qualify for NHS Continuing Healthcare funding (or if you have Continuing Healthcare funding removed at some point) it means that your care needs are deemed to be social care needs. This means the Care Act becomes relevant to you at that point – because the Care Act is largely about social care.

'Self-funders' – the term used to describe people who pay for their own care – have had a pretty raw deal in the past. They've generally been invisible to the wider health and social care system and have been left to fend for themselves, paying the highest fees for care and having little – if any – access to advice or contact from the local authority.

With the Care Act, self-funders will at least now be on the radar of the local authority. If Phase 2 of the Care Act comes in in 2020, the local authority must calculate the cost of a person's care – and keep a

record of these calculations (a care account) – regardless of how much money a person has in savings and assets, etc. This is because from April 2020 (in theory at least) a new care fees ‘cap’ will come into effect.

The ‘cap’ on care fees

The idea behind the cap is to limit the amount that any one individual over the age of 25 has to pay in total for their care to £72,000. It remains to be seen whether these figures will remain the same when/if the cap is finally put into practice.

Either way, in practice few people (probably only one in eight people) will actually benefit because:

- the cap only covers actual care costs, not living costs or accommodation costs in a care home
- the average stay in a care home is between two and three years, many people will never reach the cap, but will instead have to pay for everything
- the cost of actual care is calculated only at the rate the local authority is prepared to pay; very often this does not cover the actual cost of care.

For example, a self-funder could be paying £800/week in care fees, and yet if the local authority rate is only £500/week, it means only £500/week would be included in the care account – BUT living costs will also be deducted from this. These living costs are nominally calculated at £230 per week (approx. £12,000/year), and so in this example only £270 would actually count towards the cap (£500 less £230).

It’s easy to see that, by the time a person reaches the proposed cap, they may have paid a great deal more than £72,000.

So, in essence, the lower the local authority rate, the less is included in any care account, and so the longer it will take a person's total care costs to accumulate to reach the cap.

In the meantime the person in care will have to pay the full cost of their care – and even when they reach the cap they will still have to continue to pay all living costs and all costs of accommodation in a care home. If a person can't pay this, the local authority will help.

How will social care needs be assessed under the new system?

There will be a new system of social care assessments, and this is a contentious point about the new Care Act. In many people's views, the proposed system leaves scope for a high degree of both subjectivity and error on the part of the assessor.

But remember – and this is a vital point in relation to NHS Continuing Healthcare – if a person has care needs that are beyond the local authority's legal remit for care provision, the NHS should still provide and pay for all care – with no means testing. NHS Continuing Healthcare funding is not affected.

If a person is receiving NHS Continuing Healthcare funding, the cap is not directly relevant to them while they are receiving that funding. There should also be no cap on NHS Continuing Healthcare funding, despite some Clinical Commissioning Groups incorrectly now trying to impose one.

A person who is awarded NHS Continuing Healthcare funding may have previously been self-funding, and from April 2020 onwards any self-funded payments (for actual care) should be recorded and will count towards the cap.

A person currently receiving NHS Continuing Healthcare funding may, at some point, have that funding taken away and be deemed as needing only social care. If this happens, and if NHS funding is justified in being removed, and the person becomes self-funding, their payments for care will of course count towards the cap.

New social care assessments

Here's the controversial bit:

The amount a person may need to pay for their social care will hinge on what scores or comments one sole assessor decides to put on an assessment form. The amount of care that will count towards the cap will be only those needs that the assessor actually records and decides are 'eligible' needs.

If care needs get overlooked or missed out, the person being assessed will end up with a lower 'estimated budget', there will be less recorded in their care account, they will pay more out of their own money and they will take longer to reach the cap.

Just like with NHS Continuing Healthcare, these new social care assessments are about care needs only; they should not be an assessment of a person's money.

It is likely that local authorities will outsource the assessment of self-funders' care needs to a third party. In this there is a risk that the companies doing such care assessments may not have the skills and knowledge to properly assess needs. (And remember this is an assessment of care needs, not money.)

Such assessments and/or reassessments could even be done over the phone, again allowing scope for grave error in determining a person's

actual level of need.

Also, in any new social care assessment, the assessor **MUST** take account of potential eligibility for NHS Continuing Healthcare. However, many people fear that the people carrying out these tick-box social care assessments won't have the knowledge or experience to understand what actually constitutes eligibility for NHS Continuing Healthcare.

It means a box could be ticked to say Continuing Healthcare has been considered and discounted, when in fact the assessor has not properly evaluated the eligibility criteria for Continuing Healthcare at all.

There would seem huge scope for error here. And it would seem unlikely that any proper consideration of Continuing Healthcare eligibility could possibly be made if a self-funder is just asked a few questions over the phone by someone without professional knowledge of the person's health and nursing care needs.

Before reaching the new social care cap

Before a person reaches the social care cap, and assuming they have money and/or assets above the means test threshold, they will pay for all of their care.

Again, this does not apply to NHS Continuing Healthcare – which is not means tested.

No care costs paid before April 2020 will count towards the cap.

Top-up fees will not count towards the cap.

Any other services that are not in the original social care assessment

of eligible needs will not count towards the cap.

Interest charged by local authorities on deferred payment arrangements (see below) will not count towards the cap.

Financial help provided by the local authority towards actual care costs *will* count towards the cap.

As with Continuing Healthcare, families will need to be vigilant to ensure that their relatives are being properly assessed and that all care needs are taken into account. The number of appeals is expected to be high.

New means test thresholds from April 2020

Once a person has reached the cap, i.e. they have paid £72,000 for their actual care (excluding living costs), the local authority will provide funding based on a means test. The individual will still be responsible for paying for accommodation, general living costs, etc. – and, if applicable, care fees top up payments will still need to be paid by someone other than the local authority.

Separately from the care fees cap, new thresholds for means tested care come into effect in April 2020. Essentially:

- if property is included in the value of a person's money and assets, the new upper means test threshold will be £118,000 (currently £23,250), i.e. anyone with money above this level will pay for all of their care
- if property is disregarded (for example if a spouse still lives there), the upper threshold will be £27,000, and means tested support will be available from the local authority
- the new lower threshold (below which a person contributes only from their income, not their capital) will be £17,000

(currently £14,250).

Your care costs will be recorded in your care account regardless of how much money you have and regardless of any means test threshold. This care account is the amount you're paying for your actual care that counts towards the cap.

However, whether these figures will change by 2020 is, at the moment, impossible to say.

Universal deferred payment schemes

The new Care Act has also changed the rules about Deferred Payment Arrangements – to prevent a person having to sell their home immediately – and we cover this in a later section.

Hospital discharge and NHS Continuing Healthcare

In a later section we also look at problems families encounter when a relative is being discharged from hospital, and some of the points in this regard from the new Care Act.

One of the most common problems people encounter when being discharged from hospital and needing ongoing care is that members of hospital discharge team often seem very keen to find out about a patient's money – and yet the focus should be on the patient's ongoing care needs – not their money.

No one should be asking about a patient's money until it has been clearly shown who is responsible for paying for any ongoing care – based on care needs only.

The Care Act and NHS Continuing Healthcare

Remember these three points:

1. the Care Act does not change NHS Continuing Healthcare
2. a person needing full time care who has health needs should still be assessed for Continuing Healthcare before they pay a penny in care fees
3. prior to discharge from hospital a person should be assessed for Continuing Healthcare funding

All the recent talk about the Care Act in the press and by people in the care system could mislead people into thinking that all care is social care and all care will now be means tested. That's not the case.

NHS Continuing Healthcare is still provided by the NHS and it is not means tested – and it has nothing to do with a person's savings or property. It is provided and funded by the NHS regardless of a person's means. The Care Act does not change this.

Remember also that if your relative is eligible for NHS Continuing Healthcare, the NHS funding that follows should not only cover their healthcare and nursing care needs, but also their social care needs.

Read more about the Care Act on our website:

[Cap on social care fees postponed](#)

[The Care Act and NHS Continuing Healthcare](#)

[How the Care Act helps you with NHS Continuing Healthcare](#)

Let's put the Care Act aside for the moment and concentrate on NHS Continuing Healthcare funding...

Key things you need to know FIRST

3 DON'Ts...

1. Don't be pressured into signing any agreement with the local authority/Social Services before you understand how care fees work. This guide will help.
2. Don't be pressured into signing any full time care agreement or financial terms with Social Services before an assessment for NHS Continuing Healthcare has been done. This applies whether your relative is in hospital, in a care home or receiving care in their own home.
3. Don't be fobbed off by anyone who tells you the following things about your NHS Continuing Healthcare assessment:
 - “It's not necessary”, “It's not worth it”, “You won't get it”, “It's not relevant for you” or “You won't qualify”
 - “It's only for people at the end of their life”
 - “There's no one who can do the assessment” or “We're too busy to assess you”
 - “You can't have it because the care you need is too expensive”
 - “It's only for people who can't swallow”

These are all things that families have been told when asking for an assessment. They are all completely wrong. *Everyone* who needs full time care and who has health needs should be assessed – regardless.

And some DOs...

- If your relative is currently still at home and has not yet had any contact with the various care authorities, but you're concerned

about their welfare, you may want to contact their GP, district nurse or Social Services. At no point at this stage should any of those people ask you any questions about money. (Be aware that your relative may subsequently be informed that you have intervened.)

- Whoever you're talking to (GP, Social Services, etc.), ask them what will be done to review your relative's **health** needs. Remember, means testing (if needed) only ever happens AFTER an assessment of health needs.
- If your relative is going into a care home, an assessment for NHS Continuing Healthcare should ideally be carried out before they go into the home and before they pay a penny in care fees (see next point). The value of their property cannot be taken into account in any means testing during these first 12 weeks – if they have no other savings/assets. (Read more in section 2 of this guide.)
- Your relative should not be asked to pay any care fees until this Continuing Healthcare assessment has been done. This is the **ONLY** way the NHS or the local authority can make decisions about someone's care and who should pay for it. Health needs assessments always come before financial assessments. This often happens the wrong way round.
- Even though things may feel at crisis point and you're perhaps willing to pay for care right now so you know your relative is 'safe', it's worth reading through this guide first. Once you've agreed to pay care fees, you may lose some of your 'bargaining power' and it can take much longer to secure NHS funding. It's understandable, though, that you would want to make sure your relative is being cared for properly.

- Whenever possible, make sure you're present at all your relative's assessments. You will be at a serious disadvantage if you don't attend. Read more about assessments later in this guide.

It's worth repeating here that...

In law, nursing care for people in the UK is free at the point of use. This applies to elderly people just as much as any other citizen, no matter where the care is delivered. This has **not** changed in the NHS reforms.

Why a ‘power of attorney’ is vital

A Lasting Power of Attorney (LPA) is one of the most important documents you can have in a care situation. It allows you to act on behalf of your relative – and is invaluable when it comes to NHS Continuing Healthcare. If it’s you who is appointed power of attorney, you’ll be able to manage your relative’s affairs, should they become unable to do so.

If your relative hasn’t had a power of attorney drawn up, take action now and encourage your relative to appoint someone. There’s often a **very** quick transition between someone being capable of managing their own affairs and not being able to – and you never know when that time is coming. It could be a stroke tomorrow. Once your relative no longer has the mental capacity to make a power of attorney decision, they can no longer set one up. The result is that you will have to apply to the Court of Protection for a Deputyship order, and this takes months and is costly. Bear in mind that it can also take several months to get an LPA registered – and it must be registered in order to be able to use it.

There are two types of LPA:

- Health and welfare
- Property and financial affairs

If your relative is still mentally capable, but you’re applying for NHS Continuing Healthcare on their behalf, you don’t need a power of attorney document to act for them. You simply need their consent. However, you’re likely to need a power of attorney for many other things relating to your relative’s care, including when you’re dealing with financial institutions, so it’s helpful to have one or both types.

If your relative is no longer mentally capable of making decisions, you **do** generally need a power of attorney to act on their behalf regarding NHS Continuing Healthcare – or you need to have been appointed a Deputy for that person by the Court of Protection. If you have an LPA, it must be registered with the Office of the Public Guardian before it can be used.

[Read more here on the gov.uk website.](#)

If you have an older-style Enduring Power of Attorney (EPA), you can still use this to manage your relative's property and financial affairs, but technically you have no legal right to make decisions about their health and welfare. Many families report that the extent to which you can input into decisions about health and welfare often comes down to the degree of empathy and helpfulness any given doctor or care body has with your situation. If you're applying for or appealing for NHS Continuing Care for your relative, and you need access to care notes and assessment notes, your EPA should be accepted by the health and social care authorities – because it's all to do with funding/money.

If you have an EPA, it only needs to be registered if your relative lacks mental capacity.

If someone lacks mental capacity but has no family to represent them, an Independent Mental Capacity Advocate (IMCA) can be appointed by the local authority or NHS to act on that person's behalf. An IMCA is required to act in the best interests of the person needing care.

2: Top 10 myths about care fees

Myth no. 1: ‘People who have savings have to pay for care... ‘

WRONG!

FACT: No matter what anyone tells you about who pays for care, the decision about your relative’s care is not about how much money they have; it’s about their physical and mental *health* needs.

Just because your relative has savings, has a pension or owns their own home does not mean they necessarily have to pay for care.

If your relative has health needs... Before your relative is means-tested for **anything**, the NHS is obliged to assess them for fully-funded NHS care (NHS Continuing Healthcare). The local authority should not act in **any** financial decision-making role until this has been done.

Unfortunately, many people who actually work in the health and social care sectors are not aware of this (or perhaps choose to ignore it) and, as a result, may completely miss the point: It is an NHS matter first and foremost. Means-testing should only ever be considered once your relative has had an assessment for NHS Continuing Healthcare – with you (if you’re your relative’s representative) fully involved at every stage.

(Note: free NHS Continuing Healthcare is *not* the same as Funded Nursing Care. See later in this this guide.)

Myth no. 2: ‘Social Services can ask about money straight away...’

WRONG!

FACT: The local authority has no business asking for information about your relative’s financial situation before a proper assessment for *health* needs has been done by the NHS and you have been given the opportunity to appeal any decision that denies your relative fully-funded NHS Continuing Healthcare.

If the local authority asks you for information about your relative’s financial status and you refuse to provide it, Social Services will generally assume that your relative does have savings and that they will pay for their own care (‘self-funding’). However, no one should be asking your relative to pay for care at this point – if a Continuing Healthcare assessment hasn’t yet been carried out.

If the local authority makes the assumption that your relative is paying for care, remind them that this is about **health** first and foremost, not money. Ask them when and how exactly your relative has been assessed by the NHS for these health needs. If a local authority is trying to get you to pay for care under false pretences, it’s a serious financial offence on their part. Read more in section 4.

At no point should the local authority ask you about your own finances (as your relative’s representative), nor about the financial situation of your relative’s spouse or other relatives.

Even if you eventually agree with a decision that your relative will have to pay for their own care, you still don’t have to divulge ANY financial data to the local authority. You can simply pay for care.

However, the point at which you might **want** your relative to undergo a financial assessment is when they're running out of money and you expect the local authority to start paying for care.

Myth no. 3: 'You have to sell your home to pay for care...'

WRONG!

FACT: If NHS assessments show that your relative does need to pay for care, you still don't have to sell their house. If there are no other savings or assets, you can ask the local authority for a Universal Deferred Payment Agreement.

Let's assume your relative is going into a care home. You may not at this stage consider it a good idea to sell their home (for example if you want to rent it out) – and you cannot be forced to sell it. If your relative has no other savings, assets or income, you can ask for a Deferred Payment Agreement with the local authority with respect to the property, and the local authority will pay for care for the moment. What you are effectively doing by this is saying you will 'defer payment' of care fees until the property is eventually sold.

In such a situation, the local authority may put a Land Registry 'legal charge' on the property.

If a Deferred Payment Agreement is set up, the local authority will recoup the costs of care from your relative at a later date, when the house is eventually sold, or from their estate after their death.

These deferred payment arrangements are designed to give people a choice about whether or not to sell their home to pay for care. A person can put off the sale and the local authority will cover care costs in the meantime and then recoup costs from the sale of the property later on.

With the new Care Act local authorities will now be able to charge

interest and the agreements will only apply to people who have already used up their other money and savings down to the upper means test limit (currently £23,250, from April 2020 £27,000).

The local authority will also be able to levy an admin charge for such arrangements.

A local authority must offer a deferred payment arrangement if a person has no other funds with which to pay for care.

A word of caution

If you keep hold of your relative's home, be aware of certain potential tax implications. If your relative has been in care for some years, it's worth checking whether the tax authorities may consider their home to be a 'second residence', and the care home to be their 'primary' residence. It means that when you do eventually come to sell the property, there may potentially be a bill for capital gains tax if the property has increased in value. **Always take independent financial advice** – but make sure the adviser understands care fees well, particularly NHS funding.

Regardless of the financial side of things, always remember that if your relative has health needs, the NHS may have a duty to pay for their care anyway (through NHS Continuing Healthcare), in which case you shouldn't have to sell anything at all.

Myth no. 4: 'Anyone still living in your house has to leave...'

WRONG!

FACT: Your relative's property cannot be taken away – or taken into consideration in any means-testing – if:

- your relative's partner still lives there
- another relative over 60 lives there
- a younger relative still lives there who is incapacitated
- your relative's former partner (divorced or estranged) still lives there and is a lone parent
- a dependant under 16 lives there
- a relative over 60 lives there (or in some circumstances a friend who has been caring for your relative for some time and for whom the property has become their home)

The property may also be protected if someone else owns a proportion of it (whether they live there or not). Always take good independent financial advice before you make any decisions about property.

Also, be sure to take good advice before selling any property or other assets with the intention of avoiding care fees. You may fall foul of the rules concerning Deliberate Deprivation of Assets.

Myth no. 5: ‘The NHS only pays for care if you’re in a nursing home...’

WRONG!

FACT: Eligibility for fully-funded NHS care (Continuing Healthcare) is not based on the type of care home your relative is in. Instead, it’s based on health needs.

However, fully-funded NHS care is generally only provided if you’re receiving *nursing* care – wherever that may be provided.

If your relative is in a *residential* home (with no nursing care), your relative is **still** entitled to be assessed for NHS funding, but it may be harder to prove that they need it. It’s important to remember that it doesn’t matter who delivers the care (e.g. nursing care can be delegated to a care worker – it doesn’t have to be a nurse). What matters is the degree of health need.

So, for example, you may be in a residential home and need nursing care, and the residential home may use carers to provide what is effectively nursing care – even if the home doesn’t have registered nurses. This is fine. It still shows you need nursing care. The care home may use the services of district nurses to provide some nursing care and, of course, your relative should never be charged for this.

Bear in mind also that if your relative does start needing nursing care, and the care home *can’t* provide it at all, your relative may have to move to a care home that can provide it. So, even if your relative doesn’t need nursing care at the moment, it may be worth choosing a care home that provides it anyway. Not only can it make the pursuit of funding easier – but it means your relative won’t have to uproot again and move somewhere new.

You can also express a preference for care at home.

(Note: If your relative is already in a care home, they may be receiving Registered Nursing Care Contribution (RNCC) – also known as Funded Nursing Care (FNC). This is a weekly state allowance to cover some nursing care. If they are receiving this, and yet they've never been assessed for free NHS Continuing Healthcare, read the chapter about FNC towards the end of this guide. An assessment for NHS Continuing Healthcare should always come *before* an assessment for FNC.)

Myth no. 6: ‘The value of your home is calculated as soon as you need care...’

WRONG!

FACT: The value of your relative’s property should be disregarded in any means testing during the first 12 weeks of care – if they’re in a care home. This is called the ‘12-week property disregard’.

This means the value of the property should be removed from any calculations about care fees. This period of time is designed to give your relative a chance to get properly assessed by the NHS and, **if necessary**, for you to sort out your relative’s financial affairs. It also applies if a stay in a care home is going to be just temporary.

During these 12 weeks...

- If your relative has savings/other assets **below** the current local authority savings and capital threshold, the local authority will pay for care.
- If the local authority is paying for care, but the care home costs more than the maximum approved rate the local authority is prepared to pay for any care home placement, the local authority will pay care fees up to their maximum approved rate.
- If the care home costs more than the approved rate, and your relative has financial resources **above** the savings and capital threshold for care fees your relative will have to top up the fees *during this time*. However, there are questions about the validity of top-up fees, and you can read more about this here:
<http://www.caretobedifferent.co.uk/care-home-top-up-fees/>

- If you sell the property during these 12 weeks, the proceeds from the sale are considered fair game by the local authority from the moment you have them – and the 12-week property disregard ceases. (Keep in mind though that no one should ask you to pay care fees until you've been properly assessed for NHS Continuing Healthcare.)

After these 12 weeks...

- If your relative has savings/assets above the savings and capital thresholds, and it has been **properly** shown that they are not eligible for NHS Continuing Healthcare funding (see Section 4), it means that your relative will be asked to pay all fees.
- If, however, you have chosen not to sell your relative's property **and** your relative's total assets/savings are **below** the savings and capital threshold, the local authority should continue to pay the fees.
- Your relative can no longer top up the fees from his/her own resources after 12 weeks.
- If the care home costs more than the local authority approved rate, after 12 weeks the family is likely to be asked to pay top up fees. However, see the point above about the validity of top-up fees.

None of this negates the NHS's duty to pay for all care through NHS Continuing Healthcare if your relative's care needs are primarily health needs.

Additional points...

If your relative initially went into care on a temporary basis, the 12 week property disregard begins from the start of the **permanent** placement at the care home.

If your relative has been in care for a while and paying care fees, and then runs out of money but still owns a property, you can apply to the local authority for financial assistance. This assumes you don't want to sell the house. It doesn't matter that your relative has already been paying fees. The local authority is still obliged to apply the 12-week property disregard **from the time you ask for assistance**. Some local authorities may argue that the 12 weeks started from the time your relative first went into care, but this is false; it's from the point you ask for assistance.

The local authority should also reimburse you any costs you have incurred on account of delays on their part. They will also have to reimburse you if you have had to pay care costs as a consequence of their previous maladministration of this rule.

But remember, as before, it doesn't matter what kind of care home your relative is in, NHS Continuing Care is available no matter what the care setting is.

Myth no. 7: 'You have to cash in all your investments to pay for care...'

WRONG!

FACT: You can keep hold of all investment bonds with an element of life cover.

Your relative is **not** obliged to cash these in to pay for care – no matter how small the element of life cover.

Always take professional financial advice from an independent adviser, one who understands the specific financial issues surrounding elderly care, including NHS Continuing Healthcare.

Myth no. 8: 'You have to pay for physiotherapy in a care home...'

WRONG!

FACT: If your relative has been assessed as needing such therapies for health reasons, then he/she should not have to pay for them. They should also be provided as part of any NHS Continuing Care funding.

The NHS should provide the level of therapy needed to meet the assessed health needs.

Read more about this in section 4 of this guide.

Myth no. 9: All financial advisers can advise on long term care

WRONG!

FACT: Not all advisers are qualified or informed about the specific issues surrounding long term care.

The decisions you make about your relative's care may affect other aspects of their finances or benefits. Always take professional financial advice from an independent adviser – one who understands the specific financial issues surrounding elderly care, including NHS Continuing Healthcare.

Remember also that, even if a financial adviser seems confident your relative needs to pay for their own care, keep in mind at all times that the NHS has a legal duty to pay if your relative needs care primarily for health reasons. No one can say whether or not a person has to pay for care until an NHS Continuing Healthcare assessment has taken place.

Myth no. 10: If you need full time care you have to go into a care home

WRONG!

FACT: Your relative can choose to stay in their own home – or be somewhere else. This does not affect their eligibility for NHS Continuing Care funding.

Many health authorities seem reluctant to provide good information about receiving NHS funded care at home. However, the guidelines about Continuing Care make it very clear that this is a perfectly valid option.

Mistakes in this respect are often made at the point of discharge from hospital. Hospital discharge teams, keen to get your relative out, will often say that you have to arrange a care home place (and of course, at the same time, they'll tell you to pay for it).

This guide looks at fully-funded care at home later on.

3: What to do if...

...your relative is in hospital and needs full time care

If your relative is in hospital, make sure they're on a ward where the nurses understand their condition and needs, particularly if your relative has dementia. It sounds obvious, but it doesn't always happen.

Make sure that the bedside charts are filled in regularly – including oral intake and fluid balance charts, plus charts to monitor the risk of pressure sores. If you feel that the information on the charts does not seem to reflect what you see in your relative, raise this with the senior nurse. If the response you receive is defensive, it may indicate that time pressures or simply a lack of care are putting your relative at risk. You are entitled to complain. These notes are not only vital for the health and wellbeing of your relative, but they will be important in a funding assessment.

In hospital, families often find that they have to really push hard to find out about what assessments are being done and what's going on in the background. Many find that obstacles are put in their way, making it difficult to speak directly to the people they need to.

If you do continually push for information, however – and you know what the proper procedures are – you'll be in a much better position to secure good care for your relative.

By contacting the relevant consultants and therapists yourself, badgering them and asking questions, instead of waiting for consultants and therapists to make contact with you, you'll hopefully

find that things move more quickly. It also means that you can help make sure one person knows what the other is doing.

If your relative normally lives in a care home, but has been taken into hospital, it's logical to assume that he/she currently has what's called a 'primary health need' – where the reason for care is predominantly for health reasons. (Otherwise there would be no need to be in hospital.) If this is the case, then arguably the NHS should be picking up the bill for full time care anyway at that point.

For this reason, make sure you record of the dates of all hospital stays, including the reason for the admission and any information you receive from doctors about your relative's health and health needs. Keep this in mind as you read section 4 of this guide.

Elderly people generally fare very badly in hospital and many are discharged too soon in an attempt by the hospital to free up the bed, yet without the proper NHS Continuing Healthcare assessments having been done and without proper ongoing care arrangements having been put in place.

Hospital social workers, as part of the discharge team, are often very quick to tell someone they'll have to pay for their ongoing care – even though those social workers may know full well that the full NHS Continuing Healthcare assessment process should be carried out before anyone is charged for care.

Many families are also told that their relative will be assessed 'once they get to a care home'. Again, this could be a deliberate attempt on the part of the hospital to avoid doing proper assessments and make you cross over the line to (means tested) social care before the NHS has to pick up any further financial responsibility. When this happens,

of course, the responsibility then falls to you to challenge this and track the maladministration back to when that ‘mistake’ was made.

The new Care Act requires the NHS to notify a local authority if a person being discharged from hospital is likely to require ongoing care and support. This is called a ‘notice’ or ‘assessment notice’, i.e. a hospital is giving the local authority notice that there are ongoing care needs for which provision needs to be made.

Also, the Dept of Health’s “Care and Support Statutory Guidance” issued under the Care Act makes it clear that a person should be assessed for NHS Continuing Healthcare funding prior to their discharge from hospital. Annex G of this guidance states:

“Before issuing an assessment notice, the NHS body must have also completed any assessment of the potential Continuing Health Care needs of the patient and if applicable made a decision on what services the NHS will be providing.”

Annex H5 of this same guidance covers more about NHS Continuing Healthcare funding.

Insist on an assessment for NHS Continuing Healthcare (see Section 4) while your relative is still in hospital – and, until the proper assessments have been done, don’t let anyone convince you your relative ‘won’t be eligible’.

It is not unknown for hospital staff to stare blankly when asked about a Continuing Healthcare assessment. Many will not have heard of the process – or if they have they don’t know what the National Framework guidelines say – but this is no reason for assessments to be overlooked.

The only reason why an NHS Continuing Healthcare assessment would be delayed is if your relative is going into intermediate care and is expected to improve significantly with short-term rehabilitation. In this situation, the NHS can wait to do an assessment to see how effective the rehabilitation is before they assess ongoing needs. However, free care should still be provided in the interim – and ‘intermediate care’ does not mean your relative can simply be discharged to a care home and told to pay for care.

‘Reablement’, ‘rehab’ and ‘intermediate’ care are all funded by either the NHS or the local authority, and your relative should not be asked to pay for this.

Make sure the hospital knows you want to attend all assessments. If you have power of attorney for your relative, this should be straightforward. If you don’t, but your relative still has mental capacity to give consent to you being their representative, this should also be reasonably straightforward. If you don’t have power of attorney or consent, it can be more difficult to get to see assessment notes – but always ask. You don’t have to say up front that you don’t have power of attorney. It’s up to them to ask you.

Make the Discharge Team aware that you know about NHS Continuing Healthcare funding and what should be done. Once the Discharge Team is aware of your knowledge, they may stop pressurising you so much.

If assessments are done and it’s shown clearly that your relative is no longer NHS responsibility, the hospital will issue a ‘Section 2 notice’. This is effectively a notice to Social Services that the hospital is handing over responsibility for your relative’s care to the local authority. What this means in practice is that the NHS is shifting budget responsibility to Social Services, who will then means test

your relative. However, if your relative needs ongoing care for health reasons, this handover should only be done after a proper assessment for NHS Continuing Healthcare funding has been carried out.

The NHS wants people to occupy hospital beds for as short a time as possible, because of the cost. However, many families report that the NHS will sometimes, incorrectly, try to hand over responsibility before proper procedures and NHS funding assessment guidelines are followed. If the hospital tells you they need the bed and that your relative is 'bed blocking', remind them that it's **their** problem, not yours, and that their primary concern should be the proper care and wellbeing of your relative.

If the NHS believes someone should not be occupying a hospital bed, it may try to impose charges on Social Services for each day that the bed is occupied. There is, in theory at least, a chance that Social Services may try and charge your relative for occupying the bed – or threaten to do so. This would of course be completely illegal. You should never have to pay for care in an NHS hospital, regardless of the budgetary arguments that the NHS and the local authority might be having between themselves.

Make sure you know who the hospital discharge coordinator is for your relative and let that person know you're aware of the discharge procedures that have to be followed.

If the hospital has already issued a Section 2 notification, ask to see a copy – as your relative's representative. Make sure that everything on the form looks up to date and correct and based on a **current** assessment of health needs **and** that your relative has been assessed for NHS Continuing Healthcare. If the form is incorrect, raise this

with the hospital. They will have to withdraw the Section 2 notification and do a new one.

No one who needs any kind of ongoing care should be discharged from hospital without a proper assessment for health needs and without a full package of care in place and available to them as soon as they are discharged. There should be no gap in care.

Don't be pressured into a quick discharge from hospital. And beware – if you sign anything from Social Services you may open yourself up to paying for care, or giving them the opportunity to bill you for care.

Once your relative is out of hospital, it can be much harder to fight for care funding because you have less leverage. All the while the hospital is anxious to get your relative out, the urgency of the 'bed situation' can actually be your best bargaining tool with the various authorities. It's very sad that it should be like this, but many people report this to be the case.

Details of appeal procedures (how to challenge decisions about your relative's care) should be given to you (or to your relative) on admission to hospital.

Delayed Discharges

A 'delayed discharge' period starts from the time your relative was originally meant to be discharged (the first Section 2 notice) until the time he/she actually is discharged – **with** appropriate ongoing care.

Once a new discharge date has been decided, a Section 5 Notification will be issued by the NHS to Social Services. All rules about carrying out proper assessments remain the same.

Just to repeat...

The NHS should issue a Section 2 notice **only** once all proper health needs assessments have been completed (for NHS Continuing Care) and you have been given a chance to challenge any decisions you don't agree with.. If the NHS issues a Section 2 form before this has been done, they are in breach of clear Department of Health guidelines. Equally, if Social Services act on such a notification without health assessments having been done, they are also contravening clear guidelines.

Once your relative is ready to be discharged from hospital, make sure that on the day of discharge they are still properly cared for – and not left in a Discharge Lounge for hours. Your relative should be properly dressed and fed, given enough drinks, and have any continence needs addressed throughout.

Just because the hospital may want to free up their bed in the morning, doesn't mean the NHS can wash its hands of responsibility for care while your relative is still on the premises.

Your relative should only be sent home or elsewhere if ongoing care is in place and they will be safe at their destination, including if that's a cold and empty house.

...your relative is at home and needs full time care

If your relative is still at home but has increasing care needs, you may reach a crisis point and need to access immediate full time care. You may want to notify their GP, district nurse or social worker. If long term care in a care home is suggested by a GP, by a hospital or by another body, you can phone Social Services and ask for a list of care homes in the area. (Remember at all times that your relative can also receive full time care in their own home. The health and social care authorities will also keep a list of approved home care providers. Read more later in this guide about full time care at home.) Always remember that if Social Services are pushing you towards one particular care home, this could be to suit their own financial agenda. It may not be because the home offers the best quality care; it may not even be an appropriate care home.

No one can force your relative to go into a care home. Health and social care practitioners may not be aware of this.

As mentioned before, Social Services may ask you whether your relative will be 'self-funding'. What they're really asking here is whether your relative has any money to pay for care. **It's an unlawful question at this point**, and you don't have to answer any such questions. No decision can be made about funding until the NHS has carried out a proper assessment of your relative's **health** needs.

A quick chat from a social worker or nurse – or a few hastily noted observations or assumptions – does **not** constitute an assessment. An assessment is not a historical medical summary either. Instead, it's an up-to-the-minute assessment of your relative's health and care needs – now and in the near future – and there is a formal process to

go through over a period of time and in which you should be fully involved. (See section 4 of this guide.)

...Social Services start talking about care fees

As we've seen already, initial discussions with Social Services will almost certainly involve questions about money, and it's very unlikely that anyone will mention fully-funded NHS care (NHS Continuing Healthcare) at the outset, even though they should. Social Services will be keen to do a financial assessment to see what money your relative has.

However, your response can simply be to ask them what they are going to do to get the NHS to assess your relative for free NHS Continuing Healthcare. Be aware of the initial reply you might receive – as outlined in 'Key things you need to know first' in part I of this guide.

The local authority/Social Services should only means test once the NHS has formally (and properly) decided that your relative's care is a local authority responsibility. There should be no gap in the provision of care while the assessment (and the appeal process, if relevant) is still going on.

Read more about this in Section 4 of this guide.

...you know NHS funding is available – but you don't know what exactly

As we've mentioned before, fully-funded NHS care is called NHS Continuing Healthcare. It covers 100% of care fees, it's funded by the NHS (not the local authority) and it's based on the extent and nature of your relative's **health** needs.

If your relative does have health needs, but they are told they're not entitled to NHS Continuing Healthcare, and yet no assessment for NHS Continuing Healthcare has been done, the NHS has a duty to do an assessment – and do it properly.

Another type of NHS funding is Registered Nursing Care Contribution (RNCC) – more commonly known as Funded Nursing Care (FNC) or Free Nursing Care – available to people in nursing care homes who don't receive full NHS Continuing Healthcare.

FNC is a tax-free weekly state allowance and it's paid directly to the care home. It's supposed to cover the cost of any care your relative needs from a registered nurse. Your relative should not be considered for FNC until they've had a full assessment for NHS Continuing Healthcare. FNC is not means tested.

If anyone tells your relative they can have FNC, and yet they've not been assessed for Continuing Care, you can point out that a Continuing Care assessment always has to be done first.

See section 4 of this guide for more information on both of these types of funding.

...you start looking for a care home

Choosing a care home is an important decision. If you're at crisis point, the health and social care authorities should provide care where your relative is at the moment until you've been able to find a suitable care home. At the time it can feel as though there's a great deal of urgency about the decision. That's how many people feel, and it's tempting to make fast decisions without necessarily knowing what's what.

Remember also that care homes cannot generally provide the acute care and intervention available in a hospital.

No one can force your relative to go into a care home. If Social Services or the NHS seem to be 'pushing' a particular home, the agenda will almost certainly be because it's the cheapest – but it may not necessarily offer the best care for your relative. Some families report that Social Services have recommended wholly inappropriate care homes, purely on account of cost.

If you're being steered towards choosing a residential care home, rather than a nursing home, and yet you know your relative needs nursing care for health needs (or will do shortly), then again, this will almost certainly be about money and not the best interests of your relative.

Don't be pressured into choosing a care home quickly. It's a big decision – and it may not necessarily be the best option for your relative. An alternative option could be to have full time live-in care at home. This is covered in a separate section towards the end of part 4 of this guide.

If Social Services set up a care home placement for you without your agreement, simply tell them that *you* will be making the decision about which care home is appropriate for your relative, and that you will expect to see proper procedures followed before you even consider paying care fees. It's a good idea to put that in writing.

If Social Services or the NHS are keen to move your relative into a home before any proper assessments have been done (and you agree), make it clear that one of them will have to pay the fees, not your relative.

Don't let anyone else choose the care home. Instead, make sure you base your decision on your own visits and research.

Before your relative goes into a care home (whether they're currently in hospital or still at home), someone from the care home will do a 'pre-admission assessment' first, to make sure the home is happy (and equipped) to take them. (This is separate from any NHS or Social Services assessment.)

...your relative is already paying care fees

If your relative is already paying care fees, and you think they should be receiving fully-funded NHS care instead (NHS Continuing Healthcare) you can challenge the previous decision to charge them for care. Follow the advice in the following sections of this guide.

The first thing to do is to find out whether a proper NHS assessment has ever been done.

4: How to apply for NHS Continuing Healthcare funding

What is NHS Continuing Healthcare?

NHS Continuing Healthcare (also known as Continuing Care and fully-funded NHS care) is relevant for **everyone** at the point at which they know they need ongoing/continuing full time care.

It covers 100% of care fees in a care home or at home for someone whose needs are primarily health needs. In a care home it also covers all costs of accommodation. It is generally paid directly to the care provider by the NHS, although it is now possible to have Continuing Healthcare payments made via a Personal Budget.

Every elderly person who needs full time care and has health needs should be assessed for NHS Continuing Healthcare at the outset – and **before** they start paying any care fees.

NHS Continuing Healthcare is designed for people who have needs that need nursing and healthcare input, such as long term illness or chronic disease. The National Framework defines NHS Continuing Healthcare as follows:

“NHS Continuing Healthcare means a package of ongoing care that is arranged and funded solely by the NHS where the individual has been found to have a ‘primary health need’... Such care is provided to an individual aged 18 or over, to meet needs that have arisen as a result of disability, accident or illness.”

[This means there's no means-testing, no top-up fees and no requirement to sell your home to pay for care or to use your pension or other money or assets.]

and...

“Eligibility for NHS Continuing Healthcare places no limits on the settings in which the package of support can be offered or on the type of service delivery.”

In other words, it's available whether your relative is at home, in a care home, in a hospice, in hospital or in another location. The actual place where care is provided is irrelevant. It's the assessment of **health needs** that matters. Means-testing to establish your relative's financial position should NEVER be part of the decision-making process about eligibility for NHS Continuing Healthcare.

The funding is also available regardless of the qualifications of those delivering the care, i.e. it doesn't have to be a registered nurse who is actually delivering it; it could be a carer. What matters is the type of care and the type of needs your relative has.

This fully-funded NHS care is not just for people with physical care needs – it also applies to people with sensory disability, cognitive needs (as in dementia) and other mental health needs.

It's not the actual diagnosis that determines eligibility, but the day-to-day care needs that arise from any particular diagnosis or condition.

The NHS is obliged to provide full funding when the reason for a placement in full time care is primarily a health need and where (in the case of a care home) the care needed is more than “*incidental or*

ancillary to the provision of accommodation” (National Framework – see the section on this later on).

Essentially this means that where the care your relative needs is greater than the kind of care that Social Services normally provides (see the Coughlan case), the NHS has a duty to fund it. (Remember, Social Services cannot provide care from a registered nurse; this must be provided by the NHS – free of charge.)

NHS Continuing Healthcare can be provided on a short-term basis or for the rest of your relative’s life – or for various intervals in between. It is not indefinite funding, i.e. the NHS can decide to take the funding away if it deems that your relative’s health needs have lessened. However, this should never be done without a full and proper reassessment of all health needs – and with your full involvement and input into the process.

People who are eligible for NHS Continuing Healthcare are also entitled to access the full range of primary, secondary, community and other health services available in the UK.

In summary:

- In the case of a care home, NHS Continuing Healthcare covers ALL care fees, including the costs of accommodation and including any social care required.
- If your relative is receiving care in their own home, it covers the costs of all assessed care needs plus all personal care (bathing, dressing, etc.) plus any equipment (and potentially adaptations) deemed necessary for their care.
- If your relative receives NHS Continuing Healthcare and is at the end of their life (in ‘terminal decline’), the NHS should fund all the

supportive and palliative care needed – including pain management and provision of psychological, social, spiritual and practical support. This stage of life may require a Fast Track assessment, which is covered later on in this guide.

- NHS Continuing Healthcare is NOT the same as Registered Nursing Care Contribution (RNCC) – also known as Funded Nursing Care (FNC). Read more about that later on in this guide.

How to check if your relative has been assessed

Finding out whether or not an assessment for NHS Continuing Healthcare has been done – and then getting one done – is the most important first step.

If your relative is in a care home, ask the care home manager to arrange for a ‘Checklist assessment for NHS Continuing Care’ to be carried out. If they don’t seem to know much about it, contact the NHS Continuing Care Dept. at your relative’s local CCG directly and ask for an assessment to be done. Your relative may not yet be on their radar. If your relative is in a care home, the process should have been started automatically, however this doesn’t always happen.

If your relative is at home, you can ask the social worker or a district nurse to get the ball rolling in the same way. You can also ask a GP to refer your relative for a Checklist – however, keep in mind that not all GPs are familiar with the process.

If you contact the CCG yourself (and it’s a good idea to do this anyway), ask three questions:

1. Has an assessment for NHS Continuing Healthcare already been done? If so, when was it done and what kind of assessment was it? (If an assessment *has* been done at some point, the answer should be that it was either a ‘Checklist’ assessment or a ‘full’ assessment. More on that shortly.)
2. If your relative is already receiving full time care and no assessment has been done, ask why not. (The NHS has a duty to do this regardless of who’s currently paying for care.)
3. Ask when an assessment for NHS Continuing Care WILL be done. (During the whole Continuing Care assessment and

decision-making process, your relative's money/assets should be completely ignored.)

Alternatively, adapt the letter in the next section to suit your circumstances:

Template letter to request an assessment

To request a review of your relative's health needs and/or to find out whether an assessment for NHS Continuing Healthcare has been carried out – and carried out properly – you can adapt the letter below to suit your current situation.

Address your letter to the NHS Continuing Care Team Manager at the local CCG. If your relative is in a care home, it will be the CCG that covers the location of the care home.

Letter follows here. Adapt it to suit...

Re: Assessment for NHS Continuing Healthcare

(+ add the name of your relative, the name and location of the care home (or wherever they're receiving care) and your relationship to them, e.g. "my father/mother".)

Mymy father/mother..... is currently receiving full time care atadd name of care home – or just say 'at home'..... and is at present self-funding.

However, I do not have any information to show that he/she has been properly assessed for NHS Continuing Healthcare since needing full time care. I believe he/she may be paying for care that the NHS has a legal duty to provide free of charge.

You will be aware of the Coughlan case regarding NHS Continuing Care funding and the subsequent court judgment. Mymother/father..... has clear health needs, and I believe he/she meets the Coughlan test for fully funded NHS care. His/her needs are beyond the remit of Social Services, and so he/she should not be

means tested. You will also be aware that the provision of NHS Continuing Healthcare is not dependent on the location in which he/she is currently receiving care, but, instead, upon his/her health needs.

Please would you forward to me:

- copies of any assessments for NHS Continuing Healthcare that have been carried out since he/she started needing care onadd the date your relative started receiving full term care.....
- the full criteria against which any decisions about NHS Continuing Healthcare for mymother/father..... have been made
- an explanation of why you believe your previous decision of 'ineligible for NHS continuing care' is in line with the above Coughlan court judgement (if relevant)

I am concerned that the Coughlan test has not been applied to mymother's/father's..... case, and that, consequently, he/she is being wrongly charged for care.

If mymother/father..... has *not* been assessed for NHS Continuing Care since needing full time care, please could you advise:

- why this is the case
- when you will be arranging a Checklist assessment
- what safeguards are in place to ensure that he/she is regularly reviewed

I request that this is done without delay and that you send me copies of all communications on this matter. I would also like to attend assessments as my relative's representative.

I enclose a copy of my Lasting Power of Attorney/Enduring Power of Attorney/my relative's consent. (if relevant)

I have taken specialist advice and this letter is sent on that basis and with that guidance. I look forward to your prompt reply.

(Letter ends.)

Copy your letter to:

- the Chief Exec of the CCG
- the Director of Adult Services at your relative's local authority
- your relative's case manager at Social Services, if they have one
- your relative's GP
- the care home manager, if applicable, or the home care provider

What is the ‘National Framework’?

Whatever the **likely** outcome of any assessment for NHS Continuing Healthcare funding, your relative is still entitled to have a proper assessment carried out in order to establish what their health and care needs are. No one can claim to know that your relative won't be eligible if they haven't done a Continuing Care assessment to start with!

The law is on your side. If you're told that an assessment for NHS Continuing Healthcare does *not* need to be done, you may want to remind the various health and social care people that their obligation to assess your relative is clearly set out in the Dept. of Health's guidelines known as the [National Framework for NHS Continuing Healthcare and NHS-Funded Nursing Care](#). This link takes you to the Gov.uk website.

If you were to read through the 140 pages of the National Framework, plus the additional 91 pages of guidance notes and eligibility criteria for the various stages of the assessment process (the 'Checklist', the 'Decision Support Tool' and the 'Fast Track' process – all explained shortly), you could be forgiven for thinking that the whole assessment process is tightly controlled, that your relative's care needs are the sole focus of the process, that assessors are well trained and well versed in NHS funding responsibilities and that it all takes place within the law.

Sadly, as many thousands of families have discovered, this is very often not the case, and families find they have a battle on their hands to get things done properly and to access the funding their relatives are entitled to.

Maladministration and a discarding of the rules by many assessors and a misinterpretation of the funding eligibility criteria has led to countless people being wrongly charged for care over the years. This is what has also given rise to so many people making claims to get back care fees previously wrongly charged. In 2012 the NHS imposed deadlines on making retrospective claims (the last deadline being 31st March 2013). There may however be scope to challenge these deadlines in the courts for those prepared to pursue such a case. It is still also possible to claim back a year's worth of fees for people currently in care.

The National Framework for NHS Continuing Healthcare was first introduced in October 2007 and a new updated version was issued in November 2012 and took effect from 1st April 2013. These are the current guidelines.

The National Framework was originally supposed to streamline assessment procedures (a 'single assessment process') and create clear national decision-making guidelines for every health authority and local authority to follow. It did this by introducing standard assessment 'tools' (see later section) that all NHS assessors have to use to evaluate whether someone is eligible for NHS Continuing Healthcare funding.

All parts of the health and social care system (NHS trusts, CCGs, local authorities, the NHSCB, etc.) have a duty to comply with their responsibilities in the National Framework. Indeed, the Framework itself is supported by the [statutory Regulations and Standing Rules](#). However health authorities still seem to apply their own subjective interpretation and 'judgement' to the rules, and that's why there are still thousands of complaints, and elderly people and their families often still have to pursue a lengthy process to secure the funding.

However, keep persevering. This guide and the information on the [Care To Be Different website](#) will help you.

The best way to get the NHS and the local authority to take notice of you is when you continually make them aware that you're 'on their case', and that you know what's right and what's not – and what should and shouldn't be happening.

When you ask questions armed with information and knowledge, Social Services and the NHS will realise you know what's expected of them and they are more likely to do things correctly as a result.

What is a ‘primary health need’ – and why is it relevant?

For your relative to receive NHS Continuing Healthcare, they have to have what’s called a ‘primary health need’. The NHS (in the National Framework) states that deciding whether someone has a primary health need:

“...involves looking at the totality of the relevant needs”

...and the health and nursing care services required to meet those needs must be:

“...of a nature beyond which a local authority whose primary responsibility is to provide social services could be expected to provide...”

...and, specifically in relation to someone in a care home, a primary health need is when that person’s needs are:

“...more than incidental or ancillary to the provision of accommodation which local authority social services authority are, or would be but for a person’s means, under a duty to provide...”

In other words, a primary health need is when you need NHS care primarily because of health needs.

Plus, it must be outside the local authority’s legal remit – in other words, care that is of a nature beyond the definition of ‘social care’. One of the definition of social care can be found earlier in this guide in the section headed ‘Health vs. social care – what’s the difference and why does it matter?’

However, there is no actual legal definition of a primary health need. Nevertheless, this does not redefine the law about free healthcare. A primary health need is a concept only, drawn up in many people's view to put an obstacle between people needing long term care and the free NHS care that is available to the rest of the population.

It's also worth remembering that if any published guidance (including the National Framework) about Continuing Healthcare conflicts with the law, the law wins – every time.

A primary health need could therefore simply be described as care needs that are *primarily* health needs.

As part of the primary health need concept, the NHS has also put additional criteria in the way of NHS funding. These include assessors taking a view of the complexity or intensity or unpredictability or other characteristics in your relative's care needs. Assessing these things is wholly subjective, and we'll come back to that shortly.

This primary health need concept will be used in your relative's assessments for NHS Continuing Healthcare to clarify whether care is the responsibility of the NHS or the local authority.

However, even if your relative has clear – and significant – health needs, the NHS sets out the specific criteria for a primary health need in such a convoluted way that many people feel like giving up after the first refusal of NHS funding.

Don't give up!

The primary health need is the crux of most disputes over whether elderly care is funded free of charge by the NHS or whether someone has to pay for their own care through means testing by the

local authority. Essentially it comes down to the difference between health needs and social care needs, as outlined at the beginning of this guide. If your relative's primary need is a health need, he/she should qualify for fully-funded NHS care. Where it's not, he/she will be deemed 'ineligible'. ALL your relative's needs should be taken into account.

Fully-funded NHS care (Continuing Healthcare) for people with health needs is a matter of law, not opinion or a subjective view from an NHS team or a nurse assessor. It comes back to the Coughlan case every time. If your relative's case is not measured against the outcome of the Coughlan case, the NHS is acting illegally.

The law is crystal clear:

"The judgment in [the] Coughlan [case] clearly establishes that where a person's primary need is for health care, and that is why they are placed in nursing home accommodation, the NHS is responsible for the full cost of the package." (The Law Society)

(Note: Your relative doesn't have to be in a nursing home to receive Continuing Healthcare; they can be in any care setting, including an 'ordinary' residential home or at home.)

The Coughlan court ruling said:

"The secretary of state accepts that, where the primary need is a health need, then the responsibility is that of the NHS, even when the individual has been placed in a home by a local authority... Here the needs of Miss Coughlan... were primarily health needs for which the Health Authority [NHS] is as a matter of law responsible."

The Coughlan case also concluded that the vast majority of nursing home residents should be receiving fully funded NHS care.

However, many Continuing Care assessors and members of CCG review panels seem to ignore this. Some even hand families a sheet of paper explaining that the Coughlan case is now 'old' and therefore not relevant. Needless to say, the case is still entirely relevant.

Keep a detailed diary

When you're embarking on an application for Continuing Care funding, it's vital to keep a comprehensive record of **all** details relating to your relative's health and care, plus the conversations you have with people in the various health and care authorities, including if your relative is already resident in a care home.

This information will help enormously if you need to argue with assessors that your relative does indeed have a primary health need. Unfortunately, it's likely to be down to you to prove that they do.

It's good practice to keep these kinds of notes anyway, in case you need to take up various issues with the care provider.

It's also important to keep notes about any hospital stays, the dates, the reason for the stay plus any information or letters from your relative's clinicians and doctors that will help strengthen your case.

Read more in the section 'Vital facts and information you need' later in this guide.

How to prepare for an assessment

As we've mentioned, there are clear guidelines, published by the Department of Health, about how Continuing Care assessments should be carried out. Assessors are obliged to use a set of assessment 'tools' and to assess your relative's health needs against national minimum eligibility criteria. The assessment tools are:

- The Fast Track Pathway Tool
- The Checklist
- The Decision Support Tool

We'll be referring to them in this section and explaining each one more in later sections, too.

Your relative should ideally have a Checklist assessment for NHS Continuing Healthcare *before* going into a care home or before starting to receive full time care at home. If not, your relative will almost certainly be asked to start paying care fees – and yet the NHS may have a responsibility to pay these. So, insist your relative has an assessment for NHS Continuing Healthcare before they start paying anything.

If your relative is in hospital, they should normally have a Checklist assessment before they're discharged. See section on hospital discharge.

If your relative has not been assessed, regardless of where they are, contact the NHS Continuing Healthcare Department at your relative's local CCG. (See the example letter earlier in this guide).

If your relative has been assessed and found to be **ineligible** for NHS Continuing Healthcare, and you disagree, you can request a **reassessment**:

- if you believe their health needs do indeed warrant NHS funding and the assessors have not taken their health needs properly into account
- if an assessment process has not been followed properly
- if their health needs change

The CCG, the local authority and the NHS Commissioning Board/NHS England all have a responsibility to ensure that assessments of eligibility for NHS Continuing Healthcare – and its provision – take place in a timely and consistent manner. In practice, however, there are often frustrating delays and appalling maladministration in the process.

If a Checklist assessment has already been done, the CCG should be able to send you a copy of the Checklist, together with the notes recorded at the assessment.

If the CCG is unable to send you a copy of the Checklist, it almost certainly means it has not been done – or not been done properly. You are well within your rights to ask them to do one right away.

The Checklist is the first stage in the process. If your relative ‘passes’ the Checklist, a ‘full’ assessment will be done by the NHS, using a form called the Decision Support Tool.

Again, if the NHS team has already carried out a full assessment – and done it properly – they should be able to send you a copy of the Decision Support Tool containing all the notes recorded at the assessment.

If the NHS is unable to send you a copy of this, it almost certainly means a full assessment has not been done.

The reason we've outlined this here is to help you gauge what stage things might be at if you haven't been involved to date. It's not unusual for NHS teams to keep families in the dark – and not even tell them that an 'assessment' has taken place, which of course is quite wrong.

You may find that when the NHS realises you know how this process works, they try to do a very hurried reassessment, perhaps so they can 'tick the box' to show they've followed procedure. However, any reassessment must be done using **all** the relevant assessment tools and with you *and* the relevant health and social care professionals fully involved. (More on this later.)

Even if you're not sure if your relative will be found eligible for NHS Continuing Healthcare it's nevertheless important to get the ball rolling. It's also a specific duty of the NHS to assess your relative, in the sense that if your relative has primarily health needs, the NHS should be paying. No one should tell you your relative 'won't be eligible' or it's 'not worth it' until an assessment has been carried out.

Once you've contacted the Continuing Care Dept. asking for an assessment, you should be given a date – and enough time to prepare for it. If you can't attend on the date given, you are entitled to ask for an alternative. It's vital that you attend if your relative is to have any real chance of securing NHS funding.

Consent and advocacy

Your relative can choose to have a family member or other person present at assessments and to act as an advocate and to input on

his/her behalf. Again, if you are the power of attorney and your relative has lost mental capacity, this can be you.

Any advocate/representative should operate independently of local authority and NHS bodies and should have the opportunity to play a central role in the whole process.

Your relative's informed consent should be obtained by the NHS before the start of any assessment for NHS Continuing Healthcare. This can be done through a Mental Capacity Assessment (MCA). This is not a blanket assessment of your relative's mental or cognitive state; instead it's a way of deciding whether they're able to give consent to this particular assessment.

If your relative is of sound mind, he/she can appoint you to represent him/her at assessments and to act as an advocate in that sense. There is no need for you to have been appointed as your relative's formal power of attorney to do this. You may find, however, that NHS assessors are not always aware of this and may ask you to produce a power of attorney document. Your relative's informed consent is, however, all that's needed.

If your relative **cannot** give consent for reason of diminished mental capacity, you can still act as his/her representative/advocate, but you will probably need to show a power of attorney.

If at any point you're told you're not allowed to be involved in any assessment or review, challenge it. You're entitled to be involved at all times – and you're entitled to input into assessments. It's also worth making a note of the times the authorities try to exclude you. It will add weight to any case you make that the proper procedures haven't been followed.

Top tips

- Remember, an assessment for NHS Continuing Healthcare should be carried out **BEFORE** any discussion about Registered Nursing Care Contribution (RNCC) or Funded Nursing Care (FNC) – see later section – and certainly before any questions or discussion about money.
- If a relative or friend can attend the assessment with you, it's a very good idea. You'll have a second pair of ears and eyes – and you are entitled to take someone with you.
- You need determination – because health and social care bodies will defend their budgets aggressively and many people report that the NHS and local authority may do this regardless of whether their actions comply with the guidelines and the law.
- The more money that's at stake, the harder the NHS is likely to dig its heels in. So, be very clear about what you expect to achieve. Be bold, be vocal and be persistent – and don't take no for an answer.
- Start pulling together as much information about your relative's health and care needs as possible. Read on...

Vital facts and information you'll need

No health or social care professional is likely to know your relative as well as you do. That's why you play such a vital role in any assessment.

As you may quickly discover, when you're dealing with the NHS and the local authority, you may find yourself having to provide facts and information about your relative's health that you would normally expect to be in their general medical or care notes. *Never assume that people already know this information.* The reality is that you will often have much more accurate information than the people who are involved in your relative's care and in their assessment.

A *full* assessment (Decision Support Tool) for NHS Continuing Healthcare should be carried out by a multidisciplinary team. It may be largely up to you to make sure that the right people are actually going to attend. In that sense, **you** have to become the multi-disciplinary team coordinator, pulling together as much information as possible from as many different people as possible – because, sadly, there's no guarantee otherwise that it will be done.

Top tips

- Keep a record of what happens at every stage of an assessment – including before and after. What should happen in theory and what actually happens in practice are not always the same thing. Keep a note of any maladministration, as it can count in your favour in further appeals down the line. Procedure is **key** – and if an assessment is not done correctly, the NHS will have to do it again.

- Keep a dedicated diary from day one. You may not realise how much you'll rely on it at the start, but it will be extremely useful when you come to appeal any denial of NHS funding.
- Record all dates and times of appointments, meetings, phone calls, copies of letters and reports, conversations with staff from different organisations – and what was discussed – plus views from any therapists – **everything**. It will be invaluable.
- Keep notes about your relative's state of health: how they are and how their health is changing; things your relative says and does and any changes in character, behaviour or mood; any specific needs; things you notice about their overall health and disabilities; information on their skin, pressure sores, weight, mental clarity, speech and communication skills, hearing, sight, sleep, personal hygiene, oral hygiene, mobility and hoisting needs, ease of eating and drinking, nutritional and water intake, swallowing problems, appetite, risk of infections, continence, flexibility of joints breathing, hallucinations, medication (and its unwanted effects and impact on other things); anything unpredictable or complex, plus any general and specific risks - **everything**. Also, note how well they understand things and can make decisions. This might sound daunting – but just approach it bit by bit, for example each time you visit them just jot down some notes, including about conversations with care staff that you might have had.

You may want to bear in mind that the assessors will look at 12 care 'domains' (aspects of health) and they'll give your relative a 'score' according to the degree of need in each case. The care domains are:

1. Behaviour
2. Cognition
3. Psychological/emotional needs
4. Communication
5. Mobility
6. Nutrition – food and drink
7. Continence
8. Skin integrity (including tissue viability)
9. Breathing
10. Drugs/medication/symptom control
11. Altered states of consciousness
12. Other

Read more about these in later sections.

- Ask questions – as many as you need to ask. If you don't get a reply, ask why not. Don't agree to anything if you haven't had answers to your questions. If someone is reluctant to give you an answer it could be because the information you're asking for will help you in a way the NHS or local authority doesn't particularly relish.
- If you ask for any information and you're told it's 'not available', make a note of that – what you were asking for, who you spoke to, when you spoke to them and what their reason was for it being 'unavailable'.
- Check that all the correspondence you send and receive is dated.
- Make sure you're in the loop. Ask to be copied in on all correspondence between the different care organisations, the NHS, Social Services, GP, hospital or other clinics/therapists, where it relates to your relative's care and assessments.

- Go along to your relative's general medical appointments and take notes. Without attending these it's more difficult to gather the evidence you need to fight your corner. Ask the physician or whoever you're seeing to summarise his/her view/findings in a letter and send a copy to you. Be careful with this though – it's vital that the physician understands why you're asking and that the words they write support your relative in terms of the eligibility criteria for Continuing Care. A GP, for example, might write a summary of your relative's diagnoses, and yet what they've written doesn't highlight the day-to-day care needs and the kinds of things the Continuing Care assessors will actually be looking for. In such a case the summary could do more harm than good. Once you've read more about the Continuing Care eligibility criteria, you could offer to draft something for your GP to simply sign, assuming they're happy to.
- It's also a good idea to explore the National Institute for Health and Care Excellence (NICE) guidelines for your relative's health condition – as that can help highlight additional care that your relative may need. [You can find some of the relevant NICE guidance here.](#)

(This link opens a page on the NICE website.)

- If your relative is in a care home, ask the manager for a breakdown of those fees. This will show what you're actually paying for and it will indicate whether or not you're paying for any nursing care. Ideally it will also show how much nursing time/care is allocated to your relative, as opposed to 'personal' care or care from a care assistant. If the element of nursing care is high, this will further support your case. (Remember though that nursing care does not necessarily have to be provided by a

registered nurse. If the level of nursing care in any breakdown of fees seems very low in comparison with what you know your relative needs, it could potentially be because the home is not using nurses to deliver that care. (For someone to receive Continuing Care funding, they *don't* have to be receiving care from an actual nurse; instead, it's the actual nature of their needs that matters.)

- Get hold of your relative's care home care plan and the daily care notes. This also applies to care from a home care provider. Ask a friendly nurse or carer at the care home. Check the care plan and care notes regularly for accuracy. It's not unusual for families to find that the care notes can let them down in assessments because they don't reflect the full nature of someone's care needs. Plus, care home workers and home carers are busy people, and the care notes may be too brief to provide a full picture, including in those sections to do with daily evaluation of needs. In addition, care staff want to promote a positive picture of their care, and so they will (perhaps deliberately, perhaps not) sometimes paint an unduly positive picture of your relative's health using language that plays down needs.

Note: If you hold a Lasting Power of Attorney for your relative's property and financial affairs, but not for health and welfare matters (or if you hold an older-style Enduring Power of Attorney), and as a result the care home or care provider refuses to show you the care plan, you can challenge this point. Tell them that your pursuit of NHS Continuing Healthcare on your relative's behalf is clearly a financial matter. If they still refuse to cooperate, contact either Social Services and see if they will get hold of the care plan on your behalf. Social Services may feel they have a vested interest in helping you with this, as the more

successful you are in your quest for NHS funding, the less threat there is to Social Services budgets.

- Find out the names of as many of the following people as possible. Some may have slightly different job titles in different areas. You may not need them all, but it's useful to have them, should you need to copy your letters to different people at different levels:
 - The Continuing Care Team Manager at the Continuing Care Department of your relative's local CCG
 - Complaints Manager at the hospital and/or CCG
 - Case manager at Social Services
 - Care Coordinator/Discharge Coordinator in hospital – this is the person who coordinates assessments, liaises with a multidisciplinary team and should know what's happening when. It could be someone in the NHS or the local authority; quite often it's a social worker. It could also be a Continuing Care hospital nurse coordinator or an NHS Integrated Commissioning Manager
 - Director of Adult Services at the local authority (or it may be the Social Services Manager for Older People)
 - Your relative's GP
 - Other therapists, e.g. physiotherapist, speech and language therapist, occupational therapist, clinicians, consultants, etc.
 - Chief Executive of the local CCG
 - Chief Executive of the hospital (if relevant)
 - Local Area Team Director of the local NHSCB/NHS England

The 3 main assessment ‘tools’

The three assessment ‘tools’ that you’re likely to come across are:

1. The Fast Track Pathway Tool (used in cases of rapid deterioration or end of life)
2. The Checklist (initial ‘screening’ stage of assessment process)
3. The Decision Support Tool (used in a full assessment)

These ‘tools’ give NHS assessors a format in which to record the relevant details about your relative’s health needs during an assessment.

As we mentioned before, an assessment for NHS Continuing Healthcare looks at 12 care ‘domains’: Behaviour, Cognition, Psychological/emotional needs, Communication, Mobility, Nutrition, Continence, Skin integrity, Breathing, Medication, Altered states of consciousness and Other.

Your relative’s eligibility for NHS Continuing Healthcare is decided partly on the ‘scores’ they receive in each of these domains – and according to the overall combination of scores – and also on the overall ‘nature’ of their needs.

The Checklist looks at domains 1-11; the full assessment looks at domains 1-12. The outcome of an assessment will be based on the full picture of need, including your relative’s health needs in each domain, and also on the following broad characteristics of their needs:

- **Nature:** This means the particular characteristics of an individual’s needs (which can include physical, mental health or psychological needs) and the type of needs. It also means the

overall effect of those needs on the individual, including the type/quality of interventions required to manage them.

- **Intensity:** This relates to the extent and severity of the needs (quantity of needs and how bad they are) and to the support required to meet them, including the need for sustained/ongoing care, i.e. the continuity of care needed.
- **Complexity:** This is concerned with how the needs interact together and increase the skill required to monitor the symptoms, treat the condition(s) and/ or manage the care. This could be one single condition or two or more different ones. It may also include situations where an individual's response to their own condition has an impact on their overall needs, such as where a physical health need results in the individual developing a mental health need – and vice versa. People with a degenerative disease have complex needs by definition, but when it comes to care assessments this often seems to be overlooked.
- **Unpredictability:** This is the degree to which needs fluctuate and thereby create challenges in managing them. It also relates to the 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.

Your relative's health and care needs do not have to reflect all four types of characteristics; it could just be one. Also, your relative's health needs could be 'stable' and they may still be eligible for funding, as shown in the Coughlan case (see previous section).

To see the actual documents ('tools') the NHS Continuing Healthcare assessors may use in an assessment, read the next chapters.

Fast Track Pathway Tool

We mentioned previously that the Checklist is the first stage of the assessment. Generally speaking it is.

However, assessors should in all cases give consideration to a ‘Fast Track’ assessment.

The purpose of the Fast Track is to make a fast decision about funding if your relative’s health is deteriorating rapidly or he/she is already in ‘terminal decline’ at the end of life. The aim of the Fast Track is for urgent care and NHS care funding to be put in place straight away – and in whatever setting/location is appropriate (including at home) – regardless of any subsequent tiresome disputes over eligibility.

And so assessors must check FIRST whether a Fast Track is needed, before making the assumption they can simply start with the Checklist.

If no one has mentioned the Fast Track to you, and yet you know that your relative is rapidly deteriorating and/or in terminal decline, you can ask for your relative to be ‘fast-tracked’ for an NHS Continuing Healthcare assessment. In this situation the NHS should use the Fast Track Pathway Tool to do the assessment.

As part of the process, the NHS should also consider what actual end-of-life and/or urgent care needs to be put in place.

This tool may also be used if your relative is being discharged from hospital (for example into end-of-life care at home) and it’s clear that he/she needs some kind of urgent and immediate care. Ordinarily, a full health needs assessment would be carried out by a multi-

disciplinary team, but if there's no time to do that, then this Fast Track is used at this point.

Who completes the Fast Track form?

It's a very short form (tool) that simply asks whether your relative has a primary health need.

[You can find a link to the Fast Track Pathway Tool here.](#)

This link goes to a page on the Gov.uk website.

The Tool can be completed by an appropriate clinician. 'Appropriate clinicians' are people who are "*responsible for your relative's diagnosis, treatment or care and who are medical practitioners, such as consultants, registrars, GPs or registered nurses*" – including from the voluntary or independent sector. (National Framework page 32) – and who have the appropriate level of knowledge to make an informed decision in this respect.

If you believe you relative should be in the Fast Track process, and you are experiencing obstruction from the Continuing Care people, approach the GP or consultant directly and ask them to intervene. There's no guarantee they will agree that funding is needed and complete the form, but it's worth asking.

If your relative is at the end of their life, there are no limits on the amount of time your relative has to have left to live for them to be eligible for a Fast Track decision. In other words, it could be two weeks or nine months – the actual prognosis doesn't matter, although there should be at least some prognosis made.

If the Fast Track is used and approved and your relative has only a short time to live, the NHS should then fund care until the end.

Keep in mind though that your relative does not have to be at the end-of-life stage for the Fast Track to be used; they may 'simply' be in a period of rapid deterioration.

Once an appropriate clinician has completed and signed the Fast Track form, the CCG has to accept it and funding should be agreed and care put in place within 48 hours. Any arguments about funding should take place afterwards and should not affect your relative's immediate care. There are no care domains to assess, no scores to award, just a short form for the clinician to complete.

Care should be provided in your relative's preferred place of care. This may be at home.

This funding cannot then be taken away again without a full review of health needs.

The Checklist

If the Fast Track Pathway Tool is not relevant at the moment, the Checklist is used. This is essentially a checklist of health needs. It's supposed to be a quick way to assess whether someone **might** be eligible for NHS Continuing Healthcare funding and therefore have a full assessment. This full assessment will then be carried out using a form called the Decision Support Tool (see next chapter).

So, the Checklist is a kind of initial filter and the Decision Support Tool is for the full assessment.

The Checklist is supposed to be broad enough to pick up anyone who *might* need Continuing Care funding for full time care. However, many families feel that the Checklist is often used with the specific aim of demonstrating minimal needs and filtering people *out* of the assessment process, instead of in.

What all these processes and tools seem to skirt around is the fact that there's an elderly person here who, if care homes didn't exist, would be receiving NHS care in hospital for clear health needs – paid for by the NHS.

The Checklist assessment can be carried out by any health or social care practitioner **BUT** they must be specifically trained in using it and in evaluating the different areas it covers – and understand the eligibility criteria and the scoring system. They should also be familiar with your relative's health and care needs. It could be a district nurse, a social worker, a GP, a ward sister, a hospital doctor, etc.

As with all assessments, your relative (and you as their representative) should be informed that it's going to be used, you should have the opportunity to prepare, attend and contribute, and

you should then be informed of the outcome and given a copy of the Checklist document afterwards, complete with the assessment notes. You should also be given information on how to appeal any outcome you don't agree with.

It may be that the Checklist is not used at all in your relative's situation. If he/she has obvious health needs that look likely to attract funding there may be an immediate full assessment for NHS Continuing Healthcare using the Decision Support Tool. However, if any preliminary screening tool is going to be used at this point, it **must** be this Checklist – and no other.

When you initially ask for an assessment, the CCG should respond swiftly and the Checklist should be completed within 14 days.

[You can find the Checklist on this page.](#)

This goes to a page on the Gov.uk website.

You may find it helpful to print off the Checklist now and have a look at the descriptions of each care domain that will be assessed (pages 10-17 of the actual Checklist document).

Completion of the Checklist

The assessors will look at 11 main care domains:

1. Behaviour*
2. Cognition
3. Psychological/emotional needs
4. Communication
5. Mobility
6. Nutrition – food and drink
7. Continence
8. Skin integrity (including tissue viability)
9. Breathing*
10. Drugs/medication/symptom control*
11. Altered states of consciousness*

On the Checklist form you'll notice that each domain has three categories of need: A, B and C. A is for high needs, B is somewhere in the middle and C represents relatively low needs.

In order for the CCG to consider doing a comprehensive (full) assessment, you have to have a minimum 'score' in the Checklist:

- 2 or more 'A's
- 5 or more 'B's (or 1 A and 4 Bs)
- or at least 1 A in a domain with an asterisk *

It's a very good idea to go through the Checklist scoring yourself for your relative's health and care needs in advance of the assessment. It means that you'll be pre-armed with arguments for the scores you believe your relative should have, and you can quote the exact wording from each relevant score should you need to. Preparation is key.

After reading the Checklist criteria in advance, you may feel that your relative actually won't be eligible for Continuing Care funding. It's still worth them having the assessment though – for various reasons, including:

- It will put your relative on the NHS Continuing Care radar.
- Your own view of your relative's scores may in fact be too conservative – and they may actually pass the Checklist!
- It shows the NHS you're familiar with the process, and that's always a good thing.
- It serves as a basis from which you can demonstrate how your relative's needs are changing over time. It can form part of your evidence in that respect at a later date.
- It may show that your relative needs a weekly payment called Funded Nursing Care (see later section).

Even if your relative doesn't go on to a full assessment at this stage, you can always ask for another Checklist to be done if your relative's care needs increase at any point.

If your relative doesn't score enough in the actual assessment and you feel that the Checklist has actually been used incorrectly as a means of **disqualifying** them from having a full assessment, you can ask for the Checklist to be done again. Put this in writing to the Continuing Care Team at the CCG, and state your reasons. You can also state what scores you believe should have been awarded – but make sure those scores are high enough and that they match the combinations needed for a full assessment.

Alternatively, you can simply ask for a full assessment at this point – the one that uses the Decision Support Tool.

Despite carefully outlining the scoring levels required to get through to a full assessment, the National Framework also states that you don't have to reach the required scoring levels to go through to a full assessment! This would seem a pointless statement: not only is it vague, but it is hard to believe an assessor would adhere to it given the battle many people have getting through to a full assessment in the first place.

If your relative is in hospital or in intermediate care or rehab, the Checklist will be used once it's clear what acute needs might subside quickly with short-term rehabilitation and what ongoing needs are left that need to be assessed. If the Checklist wasn't used while your relative was still in hospital, find out when it will be.

If you think your relative's health needs will increase further in the coming months, this should be noted on the Checklist.

If your relative passes the Checklist test, it doesn't mean they'll be given NHS Continuing Healthcare funding. It just means that they can have a full assessment (see next section). Care should continue to be provided in the interim. There should not be a gap in care.

The Decision Support Tool (DST)

This is the tool that CCGs use to do a full assessment for NHS Continuing Healthcare funding. It looks at the same 11 care domains as the Checklist, plus a 12th domain: 'Other'.

The Decision Support Tool (DST) isn't the actual assessment; it's a document that records health needs, risks and scores based on information gathered by and supplied to a multidisciplinary team (MDT). An MDT meeting is then held to review and discuss all the evidence – and this is essentially the assessment that you will be attending.

All the notes made by the MDT in the assessment process are sent to the CCG afterwards, together with the team's recommendation (not decision) about whether or not your relative is eligible for Continuing Care funding.

It's the CCG that makes the final decision; the MDT itself can't do this. Instead, the MDT recommends a decision to the CCG. It is, however, unusual for the CCG to disagree with this recommendation.

That's why it's vital for you to be able to put as many arguments for funding as possible to the MDT during the meeting. In practice the decision about funding is based almost entirely on whatever's written on the form during the assessment meeting and on the scores agreed in the meeting.

All Continuing Care assessors should be trained in carrying out assessments and in using the assessment tools. They should also be aware of the landmark legal cases (such as Coughlan) relating to NHS

Continuing Healthcare and be fully conversant with the National Framework and other guidelines relevant to Continuing Care.

It's not unknown for a Continuing Care 'assessor' to be sent to do an assessment without ever having done one before and without even having read the guidelines or looked into the law. You may know more about the process than they do, and so your input can be critical.

Many assessments are carried out very badly – and this is also, no doubt, as a result of pressures on assessors to deny funding,

If all this seems rather overwhelming, keep in mind that you can only take one step at a time, and you can refer back to this guide whenever you need to.

DST: Who should be involved?

The assessment must be carried out by a multidisciplinary team (MDT) – not just one person. The MDT should include at least two professionals from health and social care – one from Continuing Care and one from the local authority, probably Social Services. Ideally, though, it will include more than just two people, because it needs to draw on all the ‘evidence’ about your relative’s health and care needs from all those involved in their care.

Under the new guidelines the Continuing Care person could be someone from an external organisation, as CCGs are now allowed to delegate this task.

Your relative’s financial circumstances do not alter the responsibility of Social Services to attend. Also, no one should ask about your relative’s finances at any point before or during this meeting.

The CCG appoints a coordinator for the process and this person should pull together the MDT. This person will probably be your main point of contact too.

As well as a Continuing Care person and social worker, the MDT could include: a hospital ward sister/lead nurse; hospital discharge nurse; Mental Health Team/dementia specialist/Community Psychiatric Nurse/clinical psychologist; therapists (e.g. SALT (speech & language), occupational therapist, physiotherapist, nutritionist, dietician etc.); consultant or other medical practitioners; continence professional; GP; care home nurse; geriatrician; live-in carer or home carer; district nurse; respite care nurse; learning disabilities team; tissue viability nurse; palliative care team; specialist nurse (e.g. Parkinson's nurse, MS nurse, respiratory nurse, pain management nurse, etc.); cancer specialist; stroke specialist; community care team

... plus of course the individual needing care (your relative) and you (their representative).

Of course, not all the above will be relevant for your relative's assessment. Alternatively, there may be other people not listed above who need to be involved. It all depends on the nature of your relative's needs. Most people find that there are around 4-6 people involved at the actual multidisciplinary assessment meeting, although there could be written input from a larger number.

Example

Let's take someone with advanced Parkinson's Disease who also has dementia, is doubly incontinent and who is very unsteady on their feet. That person might expect input into their full assessment from a Parkinson's nurse, a neurologist, falls specialist, continence specialist, Continuing Care assessor, social worker, care home nurse or home carer. Plus of course there would be input from their family or representative. Even if these health and social care people don't attend the actual assessment, although it's always better if they do, they should be asked for their view of the health and care needs in question.

ALL your relative's needs and circumstances that might affect their eligibility for funding should be taken into account.

The GP situation can be tricky. If your relative is in a care home, there may be a GP for that care home who pops in occasionally, but who doesn't actually know your relative's needs very well, if at all. In this case it can sometimes be better not to ask for the GPs input because it could simply water down the severity of your relative's care needs. It's something you'll need to make a judgement on.

The same thing could potentially apply to input from other clinicians – unless you can educate them in how their input will be used.

Prior to the assessment, find out from the Continuing Care team at the CCG who exactly will be attending, so that you're prepared. If you find there are different people in the room when you arrive, you can complain.

In summary, the MDT must draw together input about all aspects of your relative's day-to-day health and care needs and risks, and must draw on information from key professionals involved in their care. Without this input, the assessment is unsafe. There must be people involved in the assessment who have direct knowledge of your relative's needs.

No finance officers should ever be present at an assessment.

DST: What information is included?

The MDT must also review all necessary reports, charts and care notes relating to your relative's health and care needs. These reports could include:

Weight chart; medication chart; wound/pressure sore assessment chart; Barthel scores (activities of daily living); Waterlow score or Braden chart and/or tissue viability assessment (risk of pressure sores and skin breakdown); MUST Tool (malnutrition risk); Moving & Handling & Falls Risk Assessment; Community Care assessment; physiotherapy assessment; behavioural assessment; speech and language assessment (SALT); Occupational Therapy assessment; daily care notes, care plan and/or care needs 'diary'; information from GP; specialist nursing assessments; nursing assessment; psychiatric assessments/Mental Health assessment, report/summary from consultants, etc.

As before, not all of these would necessarily be relevant to your relative's situation, but there are probably more than you think.

Example

If we use the same example of someone with advanced Parkinson's Disease, dementia, double incontinence and who is unsteady on their feet, *all* the above reports and charts could be relevant. Many will form part of the daily care notes, for example the ones kept by the team at a care home or by a care provider, and you'll find them in the files. A consultant's report in this example could, for example, be from a neurologist and could summarise the severity of needs and risks.

As well as all the above – and possibly more important than some of the above – your own input is absolutely vital, and the National

Framework confirms that oral evidence should not be disregarded in an assessment.

Make sure all the information considered during the assessment is accurate and comprehensive, and that it includes both observed **and likely** deterioration of your relative's health needs in the near future.

The assessment team should comprise people with direct knowledge of your relative. However, it can come as a shock to families to discover that in some assessments, some – or even most – of the assessment team may have never even met let alone examined your relative.

Again, this is why your own input is so vital.

It's worth just taking some time to think through who you think could provide the best information about your relative's health needs. There is nothing to stop you checking whether these people do ever attend such assessments and whether they'd be prepared to do so for your relative, or at least provide written input. In fact, it would be to your relative's distinct advantage if you did. Otherwise there's no guarantee the Continuing Care assessors will actually involve them.

DST: What to expect at the actual assessment meeting

The prospect of having to sit in a room with a number of assessors and health and social care professionals and argue a case for funding is not always appealing.

The CCG should have sent you information in advance about the DST assessment process and eligibility criteria for Continuing Care. They should also inform you of the date of the DST meeting *and* give you time to prepare. If the date doesn't suit you, you can ask for an alternative.

If you're told that there will be no meeting but, instead the CCG will just look at all the evidence themselves, you can object. The National Framework is clear when it talks about a face-to-face discussion meeting needing to be held – and as near to your relative's location as possible. It should also be held in a room fit for purpose, i.e. not in a corridor or noisy/busy place.

If you get the feeling that the assessment will be a foregone conclusion, on account of the things the Continuing Care people may be saying ahead of the assessment, you can object. The only way for a funding recommendation to be reached is for all the evidence to be considered, openly and transparently, with your full involvement. Assessors have a duty to approach the DST without any preconceptions, and yet many people are told in advance that they 'won't qualify' – either to intimidate or because assessors have failed to understand the process.

The assessment usually takes place wherever your relative is currently based, e.g. a care home, their own home or in hospital.

You can take someone with you to the assessment for moral support, to be an extra pair of ears and eyes for you, and/or to make notes from a procedural point of view, i.e. are things being discussed openly and do things seem transparent.

Get there early

You will be given a specific time to attend. However, in care home situations it's becoming increasingly common for the Continuing Care assessor to get there earlier, without the family's knowledge. The assessor is likely to use this opportunity to have a look at your relative, speak to care staff and make a judgement about Continuing Care eligibility before the meetings even starts.

This hardly reflects the openness and transparency promoted so heavily in the National Framework. If you can get to the care home early yourself, even 1-2 hours earlier, so much the better. And when the assessor also arrives early, not only will you be able to monitor everything he/she says to your relative, but you can also question the assessor about why they intended to start the assessment early.

It's not unheard of for an assessor to speak to a person with dementia, ask them some questions, receive some kind of response or eye contact from that person and then note in the DST that the person understood well and was able to have a conversation. If the assessor asks several questions and the person can only give what appears to be a correct answer to just one of those questions, it's also not unheard of for the assessor to record in the notes that the person was 'able to answer questions'. Although it sounds cynical, be alert for all sorts of things like this; it's not only wholly unprofessional and a breach of all Continuing Care guidelines, but it will also pull down the final assessment scores.

Watch out for the language used

The assessor may also speak to care staff to get a quick (and often very superficial) summary of care needs. The things care staff say can be the biggest source of frustration for families; care staff will want to show that their care is good and that your relative is ‘absolutely fine’ or ‘doing really well’ or ‘settled and happy’ or ‘enjoying all the activities’. These overly positive words (if they are) will almost certainly get recorded in the assessment notes and will count against your relative. If you can talk to care staff in advance, or at least to the care home nurse you know will be in the meeting with you, tell them what the assessment is for (as they probably won’t know) and make them aware of the impact of their words. You are not asking them to be untruthful; you are simply asking them to be realistic.

Be bold

One of the MDT, probably the person from Continuing Care, will take the lead in the assessment and will take notes throughout. It’s a good idea to sit next to this person, if you can, and don’t be afraid to ask to change places with someone to make this happen.

The main assessors may never have met your relative, something that families find hard to believe, and so in the assessment you need to put forward all the relevant health needs information you want to be considered. This is why preparation is key. You may be the only reliable source of information about your relative.

As with the Checklist assessment, make sure that you’ve read the eligibility criteria BEFORE the assessment. They are different to the Checklist criteria – and scored differently. Make sure you know what scores your relative should have. More on that later.

- Go into the meeting with a confident air, even if you have to fake it.
- Look serious, even if it's not your usual nature.
- Remain detached from the assessors and be wary if they seem overly friendly. This might sound cynical, but it's easy to believe an assessor might be on your side, when very often nothing could be further from the truth.
- State at the beginning of the meeting that you expect things to be conducted in accordance with Dept. of Health guidelines, including the National Framework, and most of all the law, and mention anything you know of that has already been done incorrectly since the whole assessment process started.

Introductions

The assessors should all introduce themselves. If they don't, insist that they tell you who they are, what their job is and what their role in the assessment is.

Ask each person how familiar they are with the National Framework for NHS Continuing Healthcare. Also, ask them how familiar they are with your relative's health needs. The more the assessors realise you know what's what the better.

You could also ask them what their understanding of the Coughlan case is. If they say it's 'not relevant', they clearly don't understand the law.

If they are obviously lacking in knowledge, make sure this gets recorded on the DST. You can state that you consider the assessment to be null and void on that basis, and make sure this also gets written in the notes.

It's also a very good idea to make your own notes throughout the meeting.

Be wary if the care home nurse or home carer at the meeting is a member of the night staff, as he/she will generally only see your relative asleep and may not be able to contribute much of relevance. If you object, make sure it's written in the notes.

The discussion

The assessors will go through the DST and ask questions and make notes about various aspects of your relative's health needs. You can input with any information you want to. When you do, make sure that you observe the person taking notes actually write it down. This is where all the information you've gathered about your relative's health needs comes into its own. Take notes yourself, too.

The Department of Health states that the whole assessment process for NHS Continuing Healthcare should:

- be comprehensive
- involve a multidisciplinary healthcare team (not administrators)
- be evidence based
- draw on written and direct observations
- be holistic and look at how one need interacts with another
- be clearly documented
- involve the elderly person and (where appropriate or where requested) his/her representative/family

On this last point, very often the elderly person is not involved at all. Although this is contrary to the guidelines, it can actually be a positive thing, as it allows you to fight your relative's corner and talk about their specific health needs without feeling awkward about them being in the room with you.

Make sure the focus stays on health needs, and doesn't get side-tracked into talking about social care needs/personal care needs such as washing and dressing.

In any assessment for NHS Continuing Healthcare, or in your correspondence, it's also worth reminding the health and social care professionals involved that this process is not about budgets. It's about providing health care for health needs free of charge, as embodied in law. It's also worth letting the assessors know that you're aware of the Coughlan case and that you expect the assessors to apply the 'Coughlan test' throughout.

Summary of needs

The CCG may have suggested you submit your own summary of your relative's health needs. Some ask for it to be submitted prior to the assessment. It is a good idea to prepare something, but it may be better to hold it back until the assessment itself. Here's why:

- Having something prepared helps cement in your own mind all the points you want to make at the meeting. As a minimum, write a list of health needs and risks – and scores – in each domain, including the nature, complexity, unpredictability and intensity of those needs, so you can make sure they are all given due consideration. For a fuller report, include any maladministration in the process that you've observed – plus anything else that occurs to you as you read through the whole DST section in this guide.
- If you decide to submit this to the assessor at the meeting, make sure you've also written on it that it is not necessarily a comprehensive summary of your relative's health needs. You may have missed something out and so by saying this you are

leaving the door open for you to be able to add more evidence in due course, should you need to.

- Prior to the assessment you don't know how obstructive the assessor might be, what health needs might be glossed over, or how helpful or otherwise the other people in the MDT might be. If you submit your report to the assessor in advance, they may potentially use that to prepare counter-arguments in advance or to disregard certain evidence that could support your case – and you will have no control. By holding on to your report, but taking it to the meeting, you can present it to the assessor almost as a counter-argument to what is said and done in the assessment. You may also want to write on your report during the meeting the various instances where health needs and risks seem to have been disregarded.

To sign or not to sign?

At the end of the meeting, you may be asked to sign the DST form containing all the assessment notes. Be careful. You don't have to sign anything, and yet you may come under significant pressure to do so. It's not unheard of for an assessor to stand over a family member until they sign the assessment notes.

If you do sign the notes make sure you write next to your name that you simply attended the assessment, **not** that you agree at this point with any outcome, nor that the assessment is necessarily a comprehensive summary of health and care needs – just that you attended. It's not unknown for a signature to later be 'interpreted' as the person having agreed with the final eligibility decision – which may of course deny funding.

The assessors cannot make a decision about funding in the meeting; it has to go the CCG. The assessors may however tell you what they're going to recommend to the CCG, Again make a note of anything that you feel is intimidating or wrong. Ask them when the final decision will be made.

End the meeting as formally as you began it, saying you expect to hear from them within the National Framework timescales (see later section), and that you expect to be kept fully informed and involved.

If different sections of the DST form are for any reason completed at different times or on different days, each section should be dated accordingly with an explanation of why this has happened.

The notes on the DST will almost certainly be handwritten during the assessment. They should be legible. You'll be sent a copy – if you can't read the notes for any reason, raise this with the Continuing Care Team at the CCG.

DST: Care domains and scoring

[You can find the Decision Support Tool on this page.](#)

This goes to a page on the Gov.uk website.

At the MDT meeting, after the preliminaries, the assessors will look at each of the 12 care domains. As mentioned before, make sure you read through the eligibility criteria before the assessment (pages 21-45 of the actual DST document) and decide what scores you think your relative should be given. The letters next to each domain refer to the possible degrees of need in each case, and each domain is given one of these scores, as a means of evaluating whether your relative is likely to have a primary health need:

1. Behaviour* L M H S P
2. Cognition L M H S
3. Psychological/emotional needs L M H
4. Communication L M H
5. Mobility L M H S
6. Nutrition – food and drink L M H S
7. Continence L M H
8. Skin integrity (including tissue viability) L M H S
9. Breathing* L M H S P
10. Drugs/medication/symptom control* L M H S P
11. Altered states of consciousness* L M H P
12. Other significant care needs L M H S

N = No needs L = Low needs M = Moderate needs
H = High needs S = Severe needs P = Priority needs

The higher the scores, the more likely the NHS is to fund care.

As you can see, in some domains people are prevented from scoring ‘Severe’ or ‘Priority’ needs, no matter what their state of health. For example, someone could have extreme needs in terms of speech and communication, but because the assessment form says this is not possible, and you can only score a maximum of High, the health need is effectively downgraded and you’re less likely to be found eligible for fully-funded NHS care.

Many people find the whole scoring process ridiculous because of the way it tries to create different levels of need in what are already clear health needs! The assessment effectively tries to redefine the lower degrees of need as social needs – so that when your relative is found ineligible for NHS funding, they will be handed over to Social Services, who will means test.

All the domains should be completed during the assessment, including where deemed to be of ‘Low’ or ‘No’ needs. If the assessors are debating between themselves whether someone has a higher or lower need, they should always go for the higher of the two levels under debate. This rule is set out clearly in the National Framework guidelines.

Also, your relative shouldn’t be marked down because the required evidence or data is unavailable or inconsistent, or because a specialist is not available for comment.

Your relative should be awarded free NHS Continuing Healthcare if the assessment shows:

- a ‘Priority’ need in any of the domains where that’s possible (shown with an asterisk)
- a total of two or more ‘Severe’ scores

If your relative has one 'Severe' score, together with needs in a number of other domains, or if they have a number of domains showing High and/or Moderate needs, this may **also** indicate a primary health need and therefore eligibility, and the whole picture of need should be taken into account. This is, however, when things get even more subjective than before. You won't know for certain what the outcome is until the recommendation has gone to the CCG decision-making panel.

You may find that assessors try to diminish the severity of a health need in their comments about it. Challenge them when this happens.

Make sure risk is assessed just as much as the more obvious needs.

Take no nonsense. If you feel anything is not right or that, for example, language is being used in a certain way to trivialise health needs, say so and make sure it's actually put in the notes. Your concerns should all be noted. Sitting next to the note-taker will help.

- Don't worry about upsetting anybody.
- Don't worry about being 'difficult', just say whatever you want to say.
- Don't worry about how long it takes or about other people's time. This is your chance to have your say.

If any assessor or contributor has to leave before the end, make a note of who it was and when they left.

The 12th domain: Other

Make sure the assessors also address the 12th care domain, 'Other'. This often gets forgotten, and yet it carries a score just like the other domains. The health needs recorded in the Other domain should be considered carefully and given a legitimate score that counts towards

the final outcome. This score could be Low, Moderate, High or Severe – and a score of High or Severe in particular in this 12th domain can tip the balance into eligibility for full funding.

The guidelines state that the ‘Other’ domain should be used to record health and care needs that don’t fall into the 11 preceding categories. Most Continuing Care assessment notes are hand-written – however, this does not mean that assessors can simply use the page labelled ‘Other’ at the back of the assessment notes as additional space for notes that couldn’t be squeezed into the previous pages.

The Other domain could include things like: fluctuations in blood pressure; cardiac problems; diabetes and blood sugar issues (poorly accounted for in the Nutrition domain); some skin problems unrelated to pressure sores; extreme fatigue and/or severely disturbed sleep; oral hygiene issues; brittle/yellowing nails and associated deficiencies or infections; anaemia; nosebleeds; risk of attack from other people in care; temperature/fever; poor immune system and susceptibility to infection; problems with eye health; vomiting, dizziness and/or nausea; cholesterol issues; difficulties taking blood samples; whether someone is receiving end-of-life care (which of course may be they should be fast tracked for funding); problems with communication on account of cognitive or psychological or other mental health problems and which are poorly accounted for in the Communication domain – and indeed *anything* that has not been included elsewhere in the assessment notes and adds weight to your case for funding.

Because there are no set criteria for the scoring in this domain and the interpretation of it is wholly subjective on the part of NHS assessors. That’s why it’s vital for families to be alert to its existence and to put forward any evidence of health and care needs that fit into this domain. You can also suggest the score in this domain.

As mentioned before, the assessors also look at the nature, complexity, intensity and unpredictability of your relative's overall needs. Be prepared for this as it can have a significant impact on eligibility. (See previous section: 'The 3 main assessment tools'.)

Can the care home manager help?

Many families turn to the care home manager for support when it comes to claiming NHS Continuing Healthcare. However, many are also disappointed.

Care homes are supposed to notify the NHS when they believe someone has become eligible for NHS Continuing Healthcare, and yet many don't. Many nursing staff are unaware that they have a responsibility in this respect, many do not know about NHS Continuing Healthcare and many are simply too busy to monitor someone's health needs in this particular respect.

There's also a clear conflict of interest: It is not in most care homes' financial interest to encourage residents to claim NHS Continuing Healthcare funding because the care home usually receives higher fees from people who pay for themselves.

It's not a good situation and, again, it usually falls to you as the family to put your case together.

If you do have a sympathetic and helpful care home manager though, they can be a fantastic ally.

Timescales

There are clear timescales for the whole assessment process. As you can probably guess, though, many families report long delays in getting dates for the various stages completed.

The timescales in the assessment process should be as follows:

- If the Fast Track is requested it should be given immediate consideration and, assuming it is successful, care and care funding should be put in place within 48 hours.
- The Checklist should be carried out within 14 calendar days of being requested.
- Assuming the Checklist is successful, the full assessment (DST) *plus* the actual eligibility decision should be made within 28 calendar days of the Checklist being received by the CCG* – or sooner if your relative’s health needs become increasingly acute. (‘Received by the CCG’ means that a copy of the completed Checklist form is sent to the CCG and then the CCG receives it.)
- If the 28 days timescale cannot be met you should be given clear reasons why – and a clear idea of what timescales *will* be met.
- If your relative is found eligible for Continuing Care funding, this will be put in place with immediate effect.
- If your relative has been found eligible for Continuing Care and yet the whole process has taken more than 28* days, any care fees paid by your relative should be refunded from day 29 after the date of the original Checklist.
- Once eligibility has been agreed, the NHS will do a review after three months and then review annually. Be vigilant when they do a review, because they will be looking for any opportunities to remove funding.

- If funding is withdrawn at any point, this can only be done after a full reassessment of health needs (a full assessment) first, and with your full involvement and input.

It doesn't go unnoticed by families that the NHS seems keen to carry out reviews when there's a potential opportunity to *remove* funding, and yet will often keep families waiting months and months before an assessment is carried out with a view to *approving* funding

Assessments should take place in a timely and consistent manner

If your relative dies before an eligibility decision has been reached, the process should continue and, if your relative is found eligible for Continuing Care, any relevant refunds should be made.

Powerful tips on increasing your ‘score’ in an assessment

- In an assessment the assessors may talk about how a particular health need is being ‘managed’, e.g. in a care home. Just because a need is being managed, doesn’t make it a lesser need. All needs should be assessed, regardless of how they are currently being managed and regardless of how they may appear less severe because they’re being managed well. Well-managed needs are still needs. When a decision is made about whether or not your relative is eligible for NHS Continuing Healthcare, that decision should not be influenced by any care or treatment that is already in place. Indeed, for many conditions there is no treatment. It’s only if the successful management of a healthcare need has *permanently* reduced or removed the ongoing need that this could have a bearing on eligibility. Otherwise, all needs should be assessed as they would appear if no care were in place.
- If your relative is in a care home or receiving full time care at home, you could also make the point that if such care providers didn’t exist, your relative would be in hospital, being paid for by the NHS, because there’s a primary health need.
- Financial issues should never be part of the decision about an individual’s eligibility for NHS Continuing Healthcare.
- Make sure the focus always stays on medical and health issues, including unresolved ones, and state that your relative needs full time care *because* of these health issues.
- Check and challenge everything that’s mentioned in an assessment – and if you feel the comments are becoming more

like subjective opinion or (even worse) personal opinion than fact, say so.

- Raise your objections to any incorrect information presented. Be aware that someone may have written something a while ago in your relative's medical notes or in correspondence that is now out of date or incorrect. This will keep being used unless you point it out.
- Raise your objections if any particular health needs or issues are being glossed over or watered down.
- Remember that NHS Continuing Healthcare covers health needs arising from mental illness and dementia, as well as from physical and sensory illness.
- Always paint a picture of the worst case scenario in terms of your relative's health needs, as the assessment team will often try to do the opposite.
- Keep repeating your points until you can see they've been acknowledged and/or written down in the notes.
- Be aware of small comments or turns of phrase that could have a large bearing on the outcome. For example, if your relative is severely disabled, has zero mobility and is pushed in a wheelchair, the assessment notes may say that your relative 'uses a wheelchair to get around'. This portrays someone perfectly able to use their hands to propel themselves and who has the mental clarity to do so – and so they'll be scored lower. If your relative has severe speech difficulties and their care team has to guess what they're trying to say through body language, the notes may say that your relative is 'able to communicate his/her needs'.

Again, this gives a very misleading impression. You may see or hear phrases such as ‘has a good appetite and finishes meals’, when in fact your relative may be losing weight because they’re not getting enough nutrients in the food. A further example could be ‘will happily join in entertainment’, when in fact your relative has no comprehension of what’s going on and is completely withdrawn, but sits ‘happily’ in the corner. Be alert for every instance of things like this.

- It doesn’t matter if your relative doesn’t have a specific ‘diagnosis’ – this is all about the health/nursing needs that arise from their state of health, whatever that may be.

- Pick up on phrases that may be used in correspondence from your relative’s GP, therapists or other physicians. For example, if someone has written somewhere that your relative needs “24-hour care in a well-equipped nursing home”, that adds great weight to your case. After all, how can the NHS deny funding to someone who needs that level of nursing care? The NHS will no doubt try, but you can keep arguing the point.

- Remember, eligibility for fully-funded NHS Continuing Healthcare can be considered:
 - even if non NHS-employed staff provide the care
 - whether or not specialist staff are needed to provide the care
 - even if the person is receiving other NHS-funded care
 - even if care is being provided by a family member (remember – it’s the nature of the care that matters)
 - regardless of where the individual currently is, i.e. care home, hospice, at home, etc.
 - irrespective of the diagnosis someone may have
 - regardless of what care is already being provided

- If your relative is given high scores in enough domains to be eligible for NHS Continuing Healthcare, the NHS may then tell you that there are ‘different levels of high’ in different domains and that yours don’t add up to enough. This is completely false!
- Make sure you’re familiar with the actual phrases used in the scoring descriptions in each domain. For example, if your relative is unable to support their own weight on their feet and, in the DST for example, you believe their score should be ‘High’, be ready to quote the wording next to that score: “Completely unable to weight bear and is unable to assist or cooperate with transfers and/or repositioning”. If you can do this with each domain, it will be just that much harder for the assessors to argue with you.
- Remember to highlight risks and complexity. For example, if your relative is both immobile and doubly incontinent, their needs might include things like being unable to weight bear, unable to reposition themselves in bed, needing a urinary catheter, etc. The risks might include things like increasing pressure sores, skin breakdown, joint pain, muscle contracture, urinary tract infections, etc. Plus, all the needs and risks are increased because one thing has an impact on another (complexity). For example, incontinence often increases the risk of skin breakdown, being immobile increases the risk of constipation, having to be turned every couple of hours day and night can lead to increased anxiety and distress for someone with dementia, etc. So it’s clear in this example alone that the Mobility, Continence and Psychological Needs domains overlap. Go through each domain and think about things like this. Although it’s time consuming, it will help you.

False information you may be given – and how to respond

As mentioned at the start of this guide, most people at some point (or many times) in their dealings with the NHS and/or Social Services will be given incorrect information about the whole Continuing Care assessment process.

This may be due to ignorance on the part of the person saying it, or an attempt to prevent families claiming NHS funding.

Make a note of everything people say to you that you believe to be wrong, obstructive, deliberately intimidating or delaying. It will help your case if you can demonstrate this later.

We've listed a few examples here of things people have been told, and we've added some practical suggestions for what you can do. Our purpose here is to show how you, unfortunately, need to be on your guard at all times when dealing with health and social care authorities.

“Continuing Care doesn't apply to people with dementia.”

Completely wrong! Remind the person that NHS Continuing Healthcare is available to people with physical or mental health needs that have arisen as the result of disability, accident or illness. This naturally includes needs resulting from someone having dementia.

“Someone with severe cognitive impairment can't have any psychological or emotional needs.”

This is absolutely false. Tell the person that if a proper assessment of mental health/dementia needs had been carried out, it would be clear that there are needs in both the Cognition and Psychological Needs domains (if indeed there are). You could also point out that the

person making this statement clearly has a very poor understanding of dementia.

“Your relative’s case has already been reviewed and the procedures that were used comply with the rules.”

If this is the case, then where are the notes? And why were you not involved. Ask to see evidence to support what they’re saying and, if they can’t produce it, insist that they arrange a Checklist assessment immediately.

“You have to pay for an assessment.”

Your relative should never be charged **anything** by anyone (including by a GP) for a Continuing Care assessment.

“Your relative has already been assessed, so we don’t need to do it again.”

If you were not involved (and assessors have to involve the person being assessed and/or their representative), then they can’t have done an assessment – or at least not properly. They will have to do it again.

“You’re not allowed to see the assessment reports” or “The assessment notes are not available.”

Insist on seeing them. You are entitled to. If they still object it could be their own lack of knowledge or lack of up-to-date training, it could be because an assessment has never been done or it could be an attempt to make it as difficult as they can for you to pursue your application. Direct them to the National Framework for NHS Continuing Healthcare.

“Your relative has to pay for care until an assessment can be done.”

This is untrue. There should be no gaps in the provision of care and the *only* way to determine who is responsible for paying for that care is for a Continuing Care assessment to be carried out. You can quite rightly say that your relative is not expected to pay for care until proper procedures have been followed **and** you have been given every opportunity to appeal any denial of care funding.

“Our procedures have been checked by our solicitors and the criteria for funding had been applied properly.”

The criteria and the guidelines for assessments are available for all to see. Anyone who has been properly trained in NHS Continuing Healthcare will know this. Again, you can direct them to the National Framework for NHS Continuing Healthcare – and even point out their mistakes yourself.

“Your relative doesn’t need an assessment because we’re already providing Registered Nursing Care Contribution.” (RNCC) – also known as Funded Nursing Care (FNC)

See the chapter later on about Funded Nursing Care to find out why this statement is completely wrong.

“Your relative is not entitled to an assessment because he/she doesn’t appear to have health needs.”

If you know that your relative does indeed have health needs, ask how they’ve reached their conclusion without an assessment! Even if it ‘appears’ unlikely that someone is eligible for NHS Continuing Healthcare, no decision should be reached until the NHS has used the Checklist and/or the Decision Support Tool in the proper manner to make that judgement on a formal basis – and you have been given the opportunity to attend the assessment and see all notes.

“You won’t win.”

Be prepared for possible intimidation, obstruction, delays and excuses. Keep a note of all conversations where you feel the person in ‘authority’ is aiming to cause undue obstruction to the process.

“It’s up to you to let us know if your relative needs an assessment.”

This is wrong. If your relative goes into full time care, they should immediately come onto the radar of the health and social care authorities.

It is actually the responsibility of a care home and the NHS to notice this and it’s the responsibility of the NHS to organise the assessments, although, as many families report, this often does not happen.

(On a similar note, if you believe your relative’s needs have changed – or that it was wrong to deny NHS funding in the first place, you can ask for a review at any time.)

“It’s impossible to get the all relevant health professionals together for a multidisciplinary assessment”

This may be an excuse on the part of the Continuing Healthcare Team to save them the time of doing a proper assessment. The argument does not hold water. It may take a little bit longer to get everyone together, but it's far from impossible. Those are the rules and assessments need to be conducted in this way.

And if your relative is in hospital...

“Your relative has already been continually assessed by a multidisciplinary team while they’ve been in hospital and so the Checklist is not necessary.”

As before, if your relative has been ‘continually assessed’ for NHS Continuing Healthcare, where are the notes and the forms? Ask to see them. If they can’t produce them, request that they do a Checklist assessment immediately.

What happens next

After an assessment it's a good idea to put your own notes in order, as you'll almost certainly need to refer back to them. In the unlikely event that you're asked to send the NHS your own notes, make sure you state that they're not a comprehensive set of notes – if you choose to send them. You don't have to. There may be crucial points you didn't write down that could later become the subjects of debate and argument when it comes to decisions about funding.

Capture your thoughts

As soon as you can after an assessment, write down everything you might want to raise at a later date in terms of how the assessment was carried out, how the needs were assessed, whether there was any maladministration, coercion, intimidation, etc., whether the assessors seemed to know what they were doing, whether they knew your relative and understood their needs, whether you agreed with the scores, etc. Do it while it's all fresh in your mind. This will be invaluable later on.

Funding decision

Decisions regarding your relative's eligibility for NHS Continuing Healthcare should be made within 28 days from the original Checklist being received by the CCG, i.e. the point at which the CCG is aware that a full assessment and funding decision is required. Despite these guidelines, you may find yourself having to chase things up.

You should be sent a copy of all the notes taken at the assessment, and those notes should include who was present, in what capacity and who signed it off, plus all the health needs, the criteria used to assess your relative, and the scores recommended.

If it's a Checklist assessment you should know straight away whether your relative will be going forward for a full assessment. If it's a DST, you will need to wait until the notes have been submitted to the CCG and a decision has been made.

Once you receive that decision (in writing) it should contain clear reasoning about how exactly how the NHS has reached its decision about whether or not to provide funding and instructions on how to appeal that decision, if relevant.

If the NHS is unable to send you these assessment notes, keep chasing them up. When you do receive the notes and letter, make sure everything is clearly dated and that everything seems to reflect what was discussed at the meeting. It has been known for additional comments to be added to assessment forms afterwards, and it's also worth checking that the scores remain as discussed at the meeting. Families report that these can get changed without any further discussion, and this is of course something that should not happen.

As mentioned, the formal notes made by the assessors in the DST are passed to the CCG, along with the assessors' view about eligibility for funding, and the CCG may use a panel to consider the funding decision. The guidelines state clearly that this 'panel' should not perform a gate-keeping function or bring financial considerations into the mix. However, with CCGs now primarily motivated by money, it's hard to see how this stays out of the equation. They hold the purse strings.

There is now no absolute requirement for the CCG to use a panel to make a decision – and yet it seems unclear in the National Framework who exactly does make that decision.

The CCG will generally agree with what the assessors recommended, however if it's clear that the assessment wasn't carried out properly, the CCG can arrange for a reassessment.

While the decision is being made there should be no gap in the provision of care for your relative. This applies regardless of any arguments that might be going on between the NHS and the local authority. Your relative should never find themselves in a situation where neither the NHS nor the local authority will fund care – either separately or together – or where there is a delay in receiving treatment or having appropriate care put in place.

If the correspondence shows that your relative **is** eligible for NHS Continuing Healthcare, it means 100% of care home costs will be funded, or 100% of the cost of care at home. If your relative is already paying care fees, make sure that NHS Continuing Healthcare is backdated (see previous section). If it took a long time to get the Checklist scheduled, you could argue that funding should be backdated to when you actually requested the assessment.

Launching an appeal

If the NHS decides that your relative is **not** eligible for NHS Continuing Care, you can appeal.

The NHS should have sent you information about the formal appeals process and how to proceed. The full appeals process is outside the scope of this guide, but essentially you will need to reinforce all the 'evidence' you've gathered so far and use all the notes you made during *and after* the assessment to add further weight to your case.

The following pages will help you.

Continuing Care appeals – what to do

Here's what to do first:

- Write to the Manager or Coordinator of the NHS Continuing Care Team at the local NHS (Clinical Commissioning Group). This will be the person who arranged the DST assessment.
- State that you disagree with the outcome of the assessment
- If it was a Checklist assessment, include all the reasons why you believe the outcome is incorrect, and ask for a repeat Checklist to be carried out; you can also simply ask for a full assessment at this point, although the CCG is more likely to redo the Checklist.
- If it's the outcome of the full assessment that you disagree with, state in your letter that you will be providing arguments and evidence to support your appeal in due course.
- The NHS will no doubt reply giving you a very short time in which to do this. You can, however, remind them of the official timescales for Continuing Care reviews:
 - You have 6 months (from the date you receive the decision) to notify the local CCG that you disagree with their decision and that you're requesting a review
 - The CCG has 5 days to acknowledge in writing that it has received your request – and it must also provide you with information on the Continuing Care review process

- The local CCG must deal with your request, complete a review and make a further eligibility decision within 3 months of receiving your initial request for review. If there's a delay, the CCG must inform you in writing explaining why. It could be because they can't access the relevant care records in time or they can't pull together an appropriate multi-disciplinary team to carry out the review – but don't let them off the hook. Keep the pressure up.
- If you miss the initial 6 month deadline, but you have a good reason, you may still be able to get your case reviewed, as long as it's still possible for the CCG to access all the relevant care records, etc.
- If the CCG still denies funding and you still disagree:
- You can request an Independent Review by the regional NHS Commissioning Board – effectively, NHS England; you should do this within 6 months* of the CCG's earlier decision (the date you were notified of the decision); the Board will appoint a Chair and panel members come from within the health and social care sector, but should not be those involved in your own case.
- The Independent Review should be conducted within 3 months – unless it's found that the CCG's previous assessment for Continuing Care was not done properly OR the members of the Review Panel are not available OR the Review Panel can't get hold of the care records in time OR you request a delay yourself due to unforeseen circumstances

- The NHS Commissioning Board/NHS England should let you know of its decision within 6 weeks – and it must give you information on how to contact the Parliamentary and Health Service Ombudsman if you're still not happy.
- If the NHS Commissioning Board denies you funding, you have 12 months to contact the Parliamentary and Health Service Ombudsman to take your case further.

The CCG is responsible for informing you about the review/appeal process for Continuing Care – and it must do this at the same time as it informs you of its Continuing Care eligibility decision.

Then you need to start pulling together all the reasons why you disagree with their decision to deny funding and submit a written appeal to the same NHS Continuing Care Team.

Funding withdrawn?

Note: If your relative was previously receiving NHS Continuing Care funding and, as a result of the latest assessment, this funding is now being taken away – and yet there are no grounds for this to happen or the process of reassessment was flawed – you can argue that the NHS should continue to pay for care until your appeal has been heard and resolved. This may be a bit of a battle, but the NHS cannot simply take away funding without properly reassessing care needs, following the National Framework guidelines and upholding case law.

Further tips and advice

- General rule of thumb: If you don't agree with something, dispute it!
- Check every page of the assessment notes/report carefully and compare the information with your own notes. Some families find they have been sent 'extracts' from the notes, rather than the whole thing, with pages missing and gaps in the information. Ask for the complete document.
- If the notes are hand-written (which they almost certainly will be if they're the ones taken at the actual assessment), notice whether there's more than one style of handwriting. Some families find that additional information has been added after the assessment. If this seems strange to you, keep a note of it. If you can't read the handwriting, ask for an explanation of those parts. Don't simply assume it's accurate. It could make the difference between securing NHS funding or not.
- Pick the assessment notes apart and note any of the following:
 - mistakes in dates of diagnoses and in personal details
 - incorrect interpretation of health needs and risks
 - incomplete information and evidence
 - care domain scoring that seems to have been 'played down', thus reducing the chance of eligibility
 - misunderstandings and false assumptions
 - misstatements of fact
 - flaws in procedure that you remember
 - issues that have been overlooked
 - points to add that you weren't able to make at the assessment

- the degree to which all relevant health and social care professionals have been consulted
 - the amount of subjective opinion you notice
- Then in your appeal argue every point using all the knowledge and tips you now have from this guide and all the information you previously gathered about your relative's health. Send your letter to the Continuing Care Dept. at the CCG with a request that they review their decision. They should arrange another assessment – and go through the same process again. Copy your letter to the relevant key contacts shown earlier in this guide.
- Remember that, as the case of Pamela Coughlan showed, health care for patients in so-called 'stable yet chronic' conditions (which is most elderly people in care) may also be the responsibility of the NHS just as much as it is for people with acute needs.
- If your relative has been found ineligible for Continuing Healthcare, a decision should have been made about whether they're eligible for Registered Nursing Care Contribution (RNCC) – also known as Funded Nursing Care (FNC). This covers nursing care by a registered nurse. Make sure this is not overlooked.
- And above all, keep persevering. It can be a tough battle, and many families feel that the system is set up to make you give up – but if your relative's needs are primarily health needs, and that's the primary reason they need full time care, it's worth pursuing.

Full time care at home

NHS Continuing Care funding IS available for full time care at home – in the same way as for care in a care home. This is despite what many health and social care people may tell you. There seems to be a distinct lack of knowledge about this on the part of people inside the system, and full time care at home may rarely be mentioned unless you happen to know about it. You will almost certainly first be steered towards a care home.

The NHS may make a comparison of the costs of different models of care provision (e.g. comparing a care home place to the costs of care at home), but this comparison must be based on genuine costs for your relative, not a blanket assumption that a care home will be cheaper for the NHS to fund.

When someone receives NHS Continuing Healthcare at home, the NHS is financially responsible for all health care services, personal care services and any associated social care services that are directly related to the health and care needs that have been assessed.

Continuing Healthcare funding can also cover essential equipment that you need at home to manage care needs, and in some cases home adaptations.

Community care services are also available, as are carer support services, but keep in mind that these might be means-tested as they may be considered only **indirectly** related to the health and care needs assessed.

If you are involved in caring for your relative at home and your relative is receiving NHS Continuing Healthcare, the NHS should also consider what training needs you might have as a carer or what respite needs you have. The well-known Pointon case in 2004 is

relevant here. It involved the (then) Cambridgeshire Health Authority and South Cambridgeshire Primary Care Trust. Malcolm Pointon was a man with advanced dementia, who was cared for at home by his wife and full time carers. Mrs Pointon argued that the NHS should fund her husband's respite care at home and the Ombudsman upheld this.

The NHS may refer such needs to the local authority, but remember that the NHS may have a duty to fund carers' needs.

Care provision must also reflect your relative's individual preferences and avoid any unnecessary changes of care provider or care package, if this is likely to be detrimental to your relative – especially regarding dementia, where continuity is vital.

This can sometimes happen if care is changing from a local authority responsibility to the CCG. However, you may have to argue about this, especially if your existing home care provider is not currently on the NHS 'approved list'.

The Continuing Healthcare guidelines state that your relative's preferences should be the starting point for decisions about care provision and the actual care package.

Quote the National Framework

If care at home is an option you're keen to set up for your relative, it's worth reading through some specific paragraphs of the National Framework. You're likely to have to quote these to the health and care authorities, and so we've included the page and paragraph references here to help you:

[You'll find a link to the National Framework here.](#)

This takes you to a page on the Gov.uk website.

The paragraphs you need to look at are:

Page 10 paragraph 13

Page 17 paragraph 42

Page 21 paragraph 56

Page 33 paragraph 102

Page 47 paragraph 169

Page 53 paragraph 4.1, 4.2, 4.3 (a-f)

Page 102 paragraph 79.1, 79.2

Page 103 paragraph 79.5

Page 107 paragraph 83.2, 83.3

Page 108 paragraph 84.1, 85.1

Page 109 paragraph 86.1

Page 110 paragraph 89.1

Page 114 paragraph 95.4

Page 115 paragraph 96.4

Funded Nursing Care (FNC) or Registered Nursing Care Contribution (RNCC)

What is it – and how is it paid?

Funded Nursing Care (FNC) is also known ‘NHS-funded nursing care’ or ‘free nursing care’ or ‘Registered Nursing Care Contribution’ It is **not** the same as NHS Continuing Healthcare.

FNC is not means-tested. It’s a tax-free benefit and it’s available for people who are paying for their own care in a nursing care home. If your relative is in a nursing home and receiving any kind of nursing care – but is not eligible for full NHS Continuing Healthcare – he/she should be receiving FNC.

This is supposed to cover any care required from a registered nurse. In reality, however, at £112 per week, it covers barely a few hours of nursing care and bears little relation to the real costs of nursing people with complex health needs.

FNC is paid by the local CCG directly to the care home, and it aims to ‘reimburse’ the home for any registered nursing care they’re giving your relative.

Your eligibility for FNC is decided **after** you’ve been assessed for NHS Continuing Healthcare funding. However, many families find that their relatives have been given FNC, but have not been properly assessed for NHS Continuing Healthcare. It should be the other way round, with NHS Continuing Healthcare **always** assessed first – and a decision **not** to provide NHS Continuing Healthcare should automatically trigger a decision about FNC – and you should receive this in writing.

If your relative is receiving FNC and then subsequently receives full NHS Continuing Healthcare funding, FNC payments will stop – because the full costs of care should be being paid by the NHS anyway.

FNC and care fees – how they're related

If your relative is paying for his/her own care, FNC should result in a reduction in the overall care fees. If FNC goes up at any time, your fees should go down. However, it's important to check the care home contract: if the weekly care fees in the contract are exclusive of FNC payments, you may see no difference at all; if, on the other hand, the quoted fees are inclusive of FNC payments, the weekly care fees should decrease by the amount of the FNC payment.

Many people report seeing no difference at all. The care home contract should state clearly how this will work.

If you believe that your relative is not benefiting as they should be from FNC, take it up with the care home manager in the first instance. If that proves unsatisfactory, write to the Continuing Care Department of your relative's local CCG and copy it to the Chief executive of the CCG, the care home manager, the Chief Operating Officer of the care home's parent company (if it has one) and the Adult Services Department of the local authority.

FNC is a state benefit – which means exactly that: it should benefit your **relative**, not the care home. Care homes and care fees are supposed to be transparent, but sadly some unscrupulous practice still continues, with care homes varying their fees according to how someone pays or how someone is funded.

Attendance Allowance

FNC does not affect your relative's entitlement to Attendance Allowance. However it's always best to double check your payments as it has been known for government employees to mix up FNC with NHS Continuing Healthcare and, as a result, stop paying Attendance Allowance! (They seem to get confused because if you receive full NHS Continuing Healthcare, you no longer receive Attendance Allowance.)

FNC is not paid if your relative has to go into hospital. Your relative may still have to pay for his/her care home place during this time though, depending on their care home contract.

If your relative is not receiving FNC at all and you believe they should be, you are entitled to challenge it and to see the written Continuing Healthcare assessment that led to that original decision. Contact the Continuing Care Manager at your relative's local CCG. Remember that FNC is paid only if your relative is in a nursing home.

On the following page, you'll find a summary of the differences between NHS Continuing Healthcare and FNC:

	NHS Continuing Healthcare (CHC)	Funded Nursing Care (FNC)
Provided by:	NHS	NHS
Also known as:	'fully-funded NHS care' and 'continuing care'	'NHS-funded nursing care' and 'free nursing care' and 'Registered Nursing Care Contribution' (RNCC)
Covers:	100% of care fees, including the costs of accommodation in a care home or the costs of receiving care at home; people who receive this don't receive FNC	the element of nursing care your relative may need in a nursing care home, even if he/she isn't 'eligible' for NHS Continuing Care
How is it paid?	NHS provides care directly to the care provider or through a personal budget; there are no care bills for your relative	Paid directly to the care home; FNC should reduce your relative's care fees, depending on how the care home contract is written

Physiotherapy and other therapies – should you pay?

Many people who go into care homes are told that if they'd like physiotherapy they have to pay for it. However, if your relative has been assessed as needing physiotherapy or other therapies for health needs and as part of their care package, they should **not** have to pay for it.

If physiotherapy or other essential therapies are part of your relative's care, then the cost should be covered by the NHS, whether or not it takes place in a care home. The views of a physiotherapist (and other therapists) may not automatically be included in an assessment for NHS Continuing Healthcare, but they can be very helpful. That's why it's a really good idea to talk to the therapists(s) yourself and ask them for their view of your relative's current and ongoing needs – and if/how they are changing.

If your relative is largely immobile, then without physiotherapy they may develop chronic muscle contractures, stiffness and even more painful joints. Physiotherapy sessions could be the only time they can get on their feet and put any weight through their body, exercise their legs and stretch their back and limbs. Without physiotherapy, care staff will find it harder to care for your relative and hoisting will become a more urgent need. This is a clear health need and a clear case for physiotherapy to be funded as part of NHS Continuing Healthcare.

What to do if your relative runs out of money

This section applies if your relative is already paying care fees...

If your relative's own money reduces to the level of the local authority capital limit, Social Services will step in to pay care fees. However, they will want to protect their budgets and so, in that situation, they can be a good ally in putting pressure on the NHS to fund care.

If your relative's own money does reduce to the level of the local authority capital limit, but they still have a property to sell, you can ask for a Deferred Payment Arrangement (see earlier section) to avoid having to sell the property now.

You may also be able to apply for 'temporary financial assistance' from the local authority to bridge the gap between running out of liquid assets and selling a property. Any such temporary assistance has to be repaid once the property is eventually sold. This option of temporary assistance may change though, given the universal availability of Deferred Payment schemes via the new Care Act 2014.

Make sure you notify Social Services in good time (before your relative reaches the means test threshold) – and bear in mind that, if your relative still owns a property, there will be certain bills that you still need to pay out of your relative's funds.

These are some of the potential costs you might want to keep in mind:

- physiotherapy and other therapies
- dental checkups, treatment and insurance (if relevant)
- spectacles (especially if they get damaged in falls)
- hearing aids

- mobility and other aids not provided by the care home or Social Services
- house maintenance, regular bills and repairs
- costs of house sale and house clearing
- hair, chiropody, clothes, shoes, day-to-day items, birthday gifts, etc.
- any costs relating to dependants
- out-of pocket expenses for people acting on your relative's behalf, including fighting for NHS Continuing Healthcare

Make sure that the local authority is aware that you need to retain enough money to cover these costs.

You personally (as your relative's representative) should not have to pay care fees for your relative.

Remember, if you're disclosing financial information to Social Services, you only need to disclose information about your relative's own money/assets – or money/assets held jointly with one or more other people. You do not need to provide any information about their spouse's or family's financial matters.

And, of course, in all of this, remember that the NHS has a legal duty to fund care for health and nursing care needs, so your relative may not need to pay for care at all.

Also, you may be asked by the local authority to pay top-up fees. A top-up is the difference between the usual local authority rate for care and what the care provider charges. However, in many instances top-up fees may be inappropriate, and it's worth reading this [article about top-up fees on the Care To Be Different website](#) before you pay anything.

In conclusion – from the author...

The core values of the guidelines surrounding NHS Continuing Care emphasise choice – in the way the person receiving care would prefer to be supported and in keeping this person at the heart of the process.

The guidelines go on to stress the importance of personalisation and how assessors and practitioners should put themselves in the position of the individual needing care and consider how they, the practitioner, would feel if a particular situation were happening to them.

Assessors should also check whether they've understood what the person wants, what's important to them, now and in the future, and take full account of the individual's own views and wishes – and make those the starting point in the process.

The National Framework also seems at great pains to point out the Continuing Care assessment process is non-adversarial, and that there is no need for families to seek external advice or legal representation – and how assessments should be conducted with openness and transparency, be person-centred, give the cared-for person genuine choice and control – and so on... and so on.

For many families who are battling the system these are just empty words. It can be an exhausting battle.

However, with good advice you *can* hold the health and social care authorities to account. It may take a while to go through the process, but if you keep chipping away at every hurdle and showing the authorities that you will not give up, you can succeed.

Remember at all times that the deciding factor about eligibility for NHS Continuing Healthcare is whether or not your relative's care is outside the local authority's legal limit for providing care – and this comes from the judgement in the Coughlan case and other similar cases.

I hope you've found this guide helpful and that it will stand you in good stead as you prepare for Continuing Healthcare assessments and in challenging funding decisions you disagree with.

The NHS has just as much duty to provide care for elderly people with chronic, long term illness as it does for younger or more acute patients. The more families can challenge the various authorities to adhere to their funding obligations and provide care for long term health needs, the better it will be for all of us in the future.

Thank you again for purchasing the guide. I wish you well.

Angela Sherman