

A woman with short blonde hair, wearing a pink patterned shirt and brown trousers, is seated in a wheelchair. She is smiling and looking towards the right. The setting is an outdoor garden with various potted plants and a thatched-roof building in the background. Another person is visible in the background, working near the building.

Helping Hands  
The Home Care Specialists

Est. 1989



# Complex Care

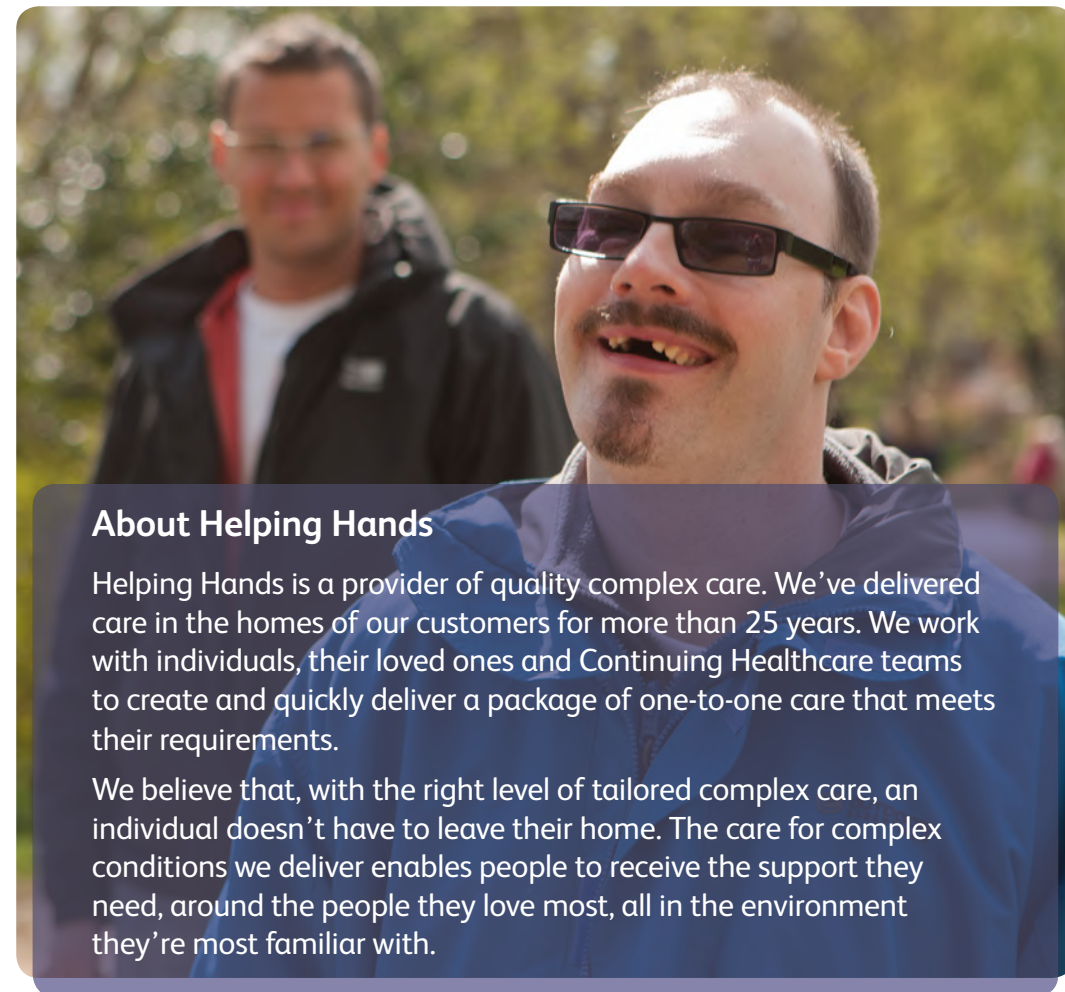
A Guide To Complex Care At Home



# Introduction to Complex Care At Home

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### About Helping Hands

Helping Hands is a provider of quality complex care. We've delivered care in the homes of our customers for more than 25 years. We work with individuals, their loved ones and Continuing Healthcare teams to create and quickly deliver a package of one-to-one care that meets their requirements.

We believe that, with the right level of tailored complex care, an individual doesn't have to leave their home. The care for complex conditions we deliver enables people to receive the support they need, around the people they love most, all in the environment they're most familiar with.

### The guide:

We've created this guide to provide you with more information on complex care at home, the funding available, the changes to personal health budgets and the forms of support offered by many providers of complex care in the UK.

### You'll find out:

- What complex care needs are
- The steps involved in applying for NHS Continuing Healthcare funding
- How personal health budgets have changed the care options available to the recipients of Continuing Healthcare
- The types of complex care that can be provided in the home



# Care in the UK

## The facts

In the United Kingdom, there are two main types of care – social care and healthcare.

### **An overview of NHS Continuing Healthcare funding**

Healthcare is provided by the NHS, meaning that those who need it receive it for free. Funding for healthcare is delivered through a care package, known as NHS Continuing Healthcare. You may see it referred to as fully-funded NHS care.

Previously this money has gone to local Clinical Commissioning Groups (CCGs), who've worked to firstly find a care provider based on the care requirements of the individual, and then with them to create a tailored package

of complex care which can be delivered as soon as possible – be it from a residential care home or a specialist home care provider.

However, this has changed slightly with the recent introduction of personal health budgets.

### **Care funding in England – a growing need**

In first quarter of 2013/2014, it was found that 57,000 patients were eligible to receive care funding through NHS Continuing Healthcare (CHC)<sup>1</sup>. During the second quarter of the year this figure was found to have increased to 59,000 patients<sup>2</sup>, displaying that there is an increasing need for complex care in England.

## What is complex care?

Complex care is a form of one-to-one care designed to cater to those affected by complex health conditions which require medium to high levels of nursing care.

The term itself is wide ranging. Depending on the condition, it can span a whole lifetime or a period of rehabilitation. It can be provided to those affected by a number of medical conditions, including, but certainly not limited to, acquired brain injuries (ABI), spinal injuries, multiple sclerosis, Parkinson's, and learning disabilities.

Unlike with standard forms of care, those affected by complex

conditions may rely on specialist pieces of medical equipment – such as ventilators, PEG feeding tubes, colostomy bags and lift transfers. So, naturally, those who provide one-to-one care of this type have to be qualified and specially trained.



*“In first quarter of 2013/2014, it was found that 57,000 patients were eligible to receive care funding through NHS Continuing Healthcare.”*

**Clinical Commissioning Groups (CCG) – A definition**  
Clinical Commissioning Groups, or CCGs, are NHS organisations responsible for commissioning or purchasing, the majority of health services in the UK.

# What's the difference between healthcare and social care?

Healthcare and social care are completely separate.

It's important to consider this when talking about NHS Continuing Healthcare.

There's no official definition for either term. And there is some crossover with the services provided by healthcare providers.



**However, the National Framework for NHS Continuing Healthcare outlines social care as:**

*“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 supporting accommodation.”<sup>3</sup>*

A healthcare need is defined in the framework, albeit not with a legal definition, as one related to “the treatment, control or prevention of a disease, illness, injury or disability, and the care or aftercare of a person with these needs (whether or not the tasks involved have to be carried out by a health professional.”<sup>4</sup>

Social care is means-tested in the majority of places across the UK, and only those people who

have a need that's classified as substantial or critical currently receive support.

Social care funding isn't available through the NHS.

Not everyone in need of care is eligible to receive Continuing Healthcare though. However, if you apply and you have a designated primary healthcare need, you'll receive care funding.

## The Coughlan Case – A landmark case in care funding

After being involved in a road accident during the 1970s, Pamela Coughlan was left needing full-time care. She was left with a number of severe physical disabilities. Until the 1990s, Coughlan's care was funded by her local authority (the East Devon Health Authority) and she received care in a residential care home.

The responsibility was then transferred to Social Services, and at the same time her care needs were reclassified as social care needs, as opposed to healthcare needs. This change meant that her care would be means-tested and she'd face the prospect of having to fund her care.

Coughlan took her case against the NHS to the High Court, winning the case in the Court of Appeal in 1999 to receive Continuing Healthcare. A landmark case, it clarified the laws around fully-funded Continuing Healthcare, with the Court of Appeal stating:

*“...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.”<sup>5</sup>*





# Care funding

## NHS Continuing Healthcare

When applying for Continuing Healthcare, people currently have to go through a two-stage assessment process.

The first involves the completion of what's known as the Decision Support Tool (DST).

The DST for NHS Continuing Healthcare is essentially an application form, which is separated into 12 separate domains – or what you'll also

see described as health needs.

They're broken down in the DST as: altered states of consciousness, behaviour, breathing, cognition, communication, continence, drug therapies and medication: symptom control, mobility, nutrition, psychological/emotional, and skin integrity.

Each of these domains is split within the DST into four

separate levels. These levels represent the need for care – ranging from absolutely no needs to high priority needs.

Once the levels of need have been determined across the 12 domains, a multi-disciplinary team (MDT) will carry out their own assessment and provide a detailed rationale to back up the claims made in the DST.

The second stage sees a CCG panel assess the application to determine whether care is fully-funded or alternatively what percentage of care funding the NHS will provide.

For an applicant to receive Continuing Healthcare funding of their nursing care:

They have to have high priority needs in at least four of these domains to receive full care funding.

Or two or more instances of needs of a severe nature across the domains to receive a percentage of the funding.

The process is slightly different in Wales, where the full amount of care funding is always provided, not just a percentage.

As soon as a DST has been approved by a CCG, care funding is provided straight away.





# Personal health budget

## The role of CCGs in selecting

CCGs have previously been responsible for sourcing and choosing the care received by an individual. They'll appoint an MDT or CHC team to a case to source care. This care is selected based on the needs of the individual and the preferred type of care – care at home, a residential care home, home hospice etc.



Changes to complex care funding However, the recent introduction of personal health budgets has given the recipient of Continuing Healthcare funding a far greater amount of choice over who delivers their care.

Personal health budgets are allocations of money given to the recipients of NHS Continuing Healthcare. They're given directly to the individual but managed by case managers, rather than the CCGs. Case managers are appointed by Continuing Healthcare.

When the budgets were first introduced, the recipients of care funding were simply given the right to ask for access to

a budget. However, they later ensured that people were given an entitlement to automatically receive one.



### The benefits of personal budgets – greater choice

The main benefit of personal health budgets is choice. Individuals previously had little choice over who provided their care – only the type of care. However, personal health budgets give them and their families the freedom and flexibility to work with their case manager to choose a care provider they feel better accommodates their lifestyles – whether it's gastrostomy nursing care at home or spinal injury care delivered at a specialist residential care home.





# Complex care at home



Unknown to many people, complex care isn't something that's limited to specially-adapted care homes. It's a very viable option for care at home. There are lots of home care agencies that offer services designed to enable people to receive the nursing care they need whilst remaining in the comfort of their own home.

Reputable home care providers, like Helping Hands, can maintain the care of a ventilated patient, continence care, gastrostomy feeding support, catheter care, as well as complex conditions, such as spinal injury support and acquired brain injury care (ABI).

For many, the process of receiving complex care at the home requires

adaptations to be made to their homes and special equipment to be installed. This is a process that a lot of complex care providers can assist with, from assessing the changes that need to be made to providing people with access to the right equipment.

# Aspects of complex care at home

There's a whole range of home-based one-to-one care available for people with complex health needs.

These include:

## Respiratory care and ventilator nursing care

Respiratory care services require a very specialist level of expertise, with trained nurses, respiratory therapists and carers working together to provide their support for people who experience breathing difficulties related to a medical condition.

There is often a large amount of specialist equipment for the right level of care to be provided – especially with ventilator care. As a result of this, it is sometimes assumed that home care isn't a realistic option.

However, this couldn't be further from the truth. Experienced providers of home-based complex care can provide carers who are fully-trained and qualified on how to deliver ventilator nursing-led care. They know how to use BiPAP (Bi-Level Positive Air Pressure), CPAP (Continuous Positive Airway Pressure) machines.



## Gastrostomy care and PEG feeding

Carers can support people who use percutaneous endoscopic gastrostomy (PEG) tubes in a number of different ways. Gastrostomy care is very much tailored to the person receiving it, catering to dietary requirements. Home carers can help people to manage their daily intake of food and fluids through regular PEG tube feeds. So, receiving it in a familiar environment on a one-to-one basis can be particularly beneficial.

## Continence care and catheter care

Many home care agencies help people affected by incontinence through continence care. Their carers help people affected experiencing incontinence in the aftermath of serious spinal and acquired brain injuries.

Continence care covers bowel management and bladder care, with the care helping to manage both medications and toilet regimes. It also includes bladder retraining, as well as support with incontinence aids, such as catheter care and help with colostomy bags and indwelling urethral catheters.

A sensitive issue, it's often easier for people to receive continence support in the home, an environment they're completely familiar and comfortable with.



# The benefits of opting for home-based one-to-one nursing care

Choosing between a service that can deliver nursing care in the home, a residential care home, a hospice and a day care centre isn't easy. Individuals and their families are likely to have lots of questions.

However, there are lots of benefits to opting for a one-to-one nursing-led care service:

## Complex care at home

Moving to a new location is tough at the best of times – there's always so much to get used to. It's even harder for those who have complex care needs. A home-based nursing-led care service enables individuals to remain in their own home – an environment they know better than any other. With this, they don't have to adapt to new surroundings – as they would if they were to go to a residential care home.

It also means that loved ones can continue to visit on a more consistent basis.



## Friendship

Although carers are primarily there to provide complex care, they're also around to offer their companionship. Some care providers, like Helping Hands, look to pair people with a carer who shares similar interests, likes and dislikes. This approach allows them to quickly find common ground, and sees bonds and friendships that last year's being formed.

## A familiar face – consistency in care

Consistency is important in all forms of care. With a home care service, nursing-led care is usually delivered by one or two carers – rather than a large team working on a rota basis. This means that the individual gets a level of consistency, which in itself results in less disruption to the routines they're so used to. It allows the person to know they've got another person, in addition to loved ones, that they can really rely on.

## Tailored to the individual – one-to-one care

Home-based nursing-led care is very similar to live-in care. There is only one person receiving care in that environment, meaning their needs are the main focus. If your loved one is receiving nursing-led care in their own home, you can feel confident that their medical requirements are being fully met. Complex care plans can be quickly adapted to ensure that the right level of care is provided.



## Commission a carer independently or use a managed service?

With the introduction of personal health budgets and the freedom that they bring, people now have more choice over the provider of their own or their loved one's care. There are more options that can be explored – from commissioning care from an independent carer to a provider of home care.

Under the current Continuing Healthcare framework, you can't

directly employ a carer. All care has to be commissioned by a CCG, or in the case of personal health budgets, a case manager. So, whether you or a loved one are looking to employ an independent carer, get care from a residential care home or a specialist home care provider – it has to be commissioned.

There are a number of benefits to using a managed service (i.e. a care agency or a care home) over commissioning care from an independent source:

- **Monitored by the Care Quality Commission (CQC)** – All providers of care in the UK are monitored by the Care Quality Commission (CQC). They're the body responsible for establishing care standards and making sure that they're met. Its annual inspections are visible to members of the public, allowing people seeking care to see whether a care provider meets these standards. Care services that are reputable are registered with the CQC. On the other hand, an independent carer may not be.
- **Qualified and trained on an on-going basis** – Complex care isn't something that can be delivered without any prior training or qualifications. Specialist training is required on pieces of equipment, like BiPAP machines, and procedures, such as PEG tube feeding. Many managed care services will put their staff through training on an on-going basis to ensure they have and continue to develop the best skillset to deliver complex care.
- **A replacement carer if a regular carer falls ill** – With an independent carer, you have no assurances that a replacement will be able to step in if they happen to fall ill, for example. This is something that managed care services are well prepared and experienced in dealing with. They'll provide an experienced replacement – someone who's trained to deliver specific levels of complex care – at short notice.
- **Personal liability cover is dealt with** – Care providers have to have personal liability cover in place to cover their staff. They manage this directly themselves. You don't have to worry about it. However, with an independent carer, you do.
- **Pay one care bill with payments managed** – All HMRC and National Insurance contributions for carers provided by a managed service are dealt with by the business. Records and documentation is kept up to date, whilst payments are made when necessary. If you commission an independent carer, there are multiple bills and payments to be dealt with. It's an additional time consumer and it can be quite complicated.



# Need more information on complex care or Continuing Healthcare?

We hope, through this guide, we've made you more aware of the Continuing Healthcare funding that's available for people affected by complex conditions, the steps involved in the assessment process and the introduction of personal health budgets.

However, if you have any questions or you want to find out more about complex care at home or care funding through NHS Continuing Healthcare, contact our complex care team. They're happy to talk you through the steps involved in applying for funding, the types of home-based care available for complex health conditions and much more.



To speak to a member of Helping Hands' complex care team, call 0808 180 1091, or visit

<http://www.helpinghandshomecare.co.uk/complex-care.aspx>

*This guide has been produced by Helping Hands, a UK-based provider of one-to-one complex care, fast-track palliative care, respite care, home care and live-in care.*

*If you want to find out more about Helping Hands and its range of home care services, visit:*

<http://www.helpinghandshomecare.co.uk/>

## References:

1. <http://www.hscic.gov.uk/catalogue/PUB12715>
2. <http://www.hscic.gov.uk/catalogue/PUB13345/nhs-cont-heal-act-eng-q2-2013-14-exp-rep.pdf>
3. [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/213137/National-Framework-for-NHS-CHC-NHS-FNC-Nov-2012.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213137/National-Framework-for-NHS-CHC-NHS-FNC-Nov-2012.pdf)
4. [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/213137/National-Framework-for-NHS-CHC-NHS-FNC-Nov-2012.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213137/National-Framework-for-NHS-CHC-NHS-FNC-Nov-2012.pdf)
5. [http://www.carelaw.co.uk/example\\_cases.htm](http://www.carelaw.co.uk/example_cases.htm)