

Palliative Care

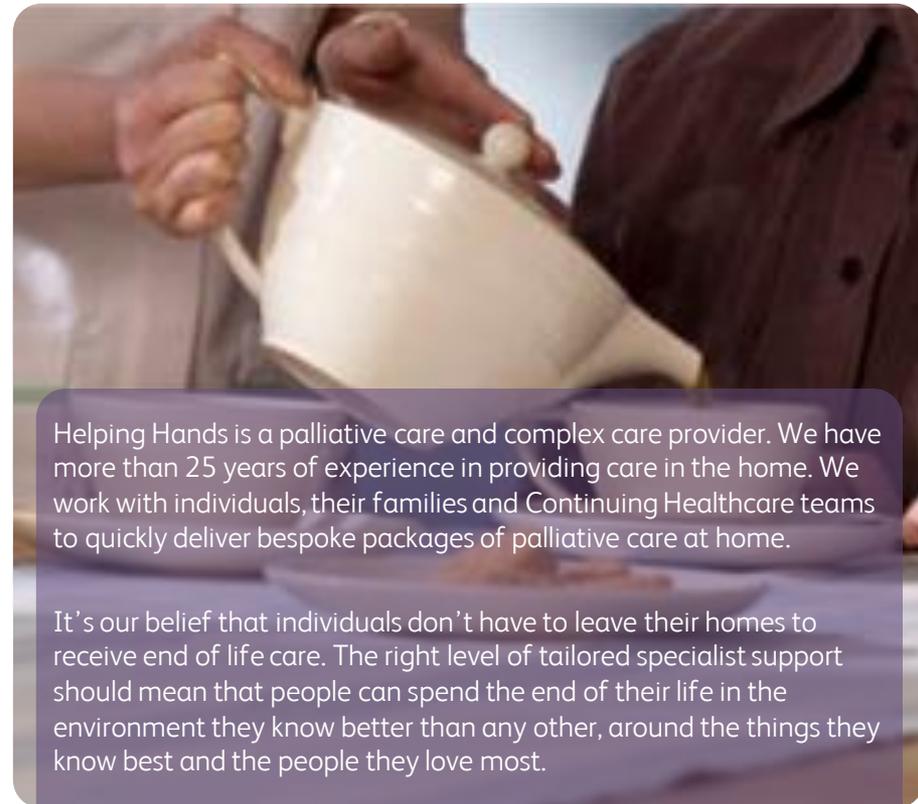
Talking About End of Life Care



Introduction to Palliative Care

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Helping Hands is a palliative care and complex care provider. We have more than 25 years of experience in providing care in the home. We work with individuals, their families and Continuing Healthcare teams to quickly deliver bespoke packages of palliative care at home.

It's our belief that individuals don't have to leave their homes to receive end of life care. The right level of tailored specialist support should mean that people can spend the end of their life in the environment they know better than any other, around the things they know best and the people they love most.

The guide:

This guide has been created to provide you with the facts about palliative care, the funding support that's available, and the different types of palliative care services in the UK.

You'll find out:

- Who's eligible for funding through Continuing Healthcare.
- The benefits of using a service that provides this type of care at home.
- Why it's beneficial to opt for a managed service over directly employing a carer.



The need for palliative care in the UK

The facts

Seeing a family member or friend impacted by a terminal or life-threatening illness is one of the hardest things we can experience.

As a loved one, you want to ensure that the final stages of their life can be lived in as much comfort as possible, free of pain and distress, through medical and emotional support – provided by family members and professional carers.

The support delivered at the end of a life is often referred to

as *end of life care* or *palliative care*, and it's been estimated that between 355,000 and 457,000 individuals require this support every year¹.

However, it's also been estimated that between 92,000 and 142,500 people who need palliative care, don't receive it².

One of the reasons why individuals don't receive the care they need may be related to care funding and the lack of awareness that often surrounds it.

What is palliative care?

Palliative care is provided for individuals affected by life-limiting or life threatening conditions that can't be cured through treatments.

It's not always short term, however.

Although it's often provided to people for a relatively short period of time at the end of their lives, it can last anywhere from a couple of days to a number of years.

At its core is a person-centric form of care that seeks to improve the quality of life experienced by people impacted by these illnesses.

Through symptom control, carers work to ensure that the recipient of care is able to live

life with as much fulfilment and comfort as possible, by relieving pain and distress.

Palliative care isn't just medical support, and it isn't just provided for the individual.

It also encompasses emotional support, helping both patients and families to cope with the complex issues and concerns associated with end of life.



The World Health Organisation (WHO) palliative care definition states that it “integrates the psychological and spiritual aspects of patient care,” but also “intends neither to hasten or postpone death.”³

Palliative care funding – who provides it and who’s eligible?

Continuing Healthcare funding

In England and Wales, people who require on-going healthcare away from a hospital environment are entitled to receive funding from the NHS, through NHS Continuing Healthcare (CHC) packages.

You may see it referred to as fully-funded NHS care.

Who’s eligible for Continuing Healthcare?

Not everyone with a complex medical condition will be eligible to receive funding for their care.

However, in palliative cases, everyone is.



Continuing Healthcare funding is determined by an assessment.

There are **two** types of assessment:

The Decision Support Tool for NHS Continuing Healthcare and the Fast Track Pathway Tool for NHS Continuing Healthcare.

The Decision Support Tool (DST) for NHS Continuing Healthcare

As an assessment the *Decision Support Tool (DST) for NHS Continuing Healthcare* covers 12 separate domains – or health needs: behaviour, cognition, psychological/emotional, communication, mobility, nutrition, continence, skin integrity, breathing, drug therapies and medication: symptom control, and altered states of consciousness.

Each domain is assessed individually, with four levels of need – ranging from no needs to high priority needs.

In order to receive Continuing Healthcare funding, an applicant has to have high priority needs in four of these domains, or two or more instances of severe needs across the domains.

These needs are assessed by a multi-disciplinary team (MDT), who will provide a rationale for each of the decisions they’ve made in the DST to back the claims up.

The DST is then reviewed by CCGs (Clinical Commissioning Groups).



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.

Palliative care funding – who provides it and who’s eligible?

Palliative care cases – fast track Continuing Healthcare funding

However, those with rapidly deteriorating conditions can apply to receive Continuing Healthcare funding straight away – using the *Fast Track Pathway Tool For NHS Continuing Healthcare*.

A rapidly deteriorating condition is considered to be a priority health need.

Completed by a clinician, this DST requires a statement that outlines the individual’s present condition together with evidence from assessments, diagnosis and prognosis, as well as details of needs – both short and long term – as well as any expected deterioration.



It ensures that individuals can be discharged from hospital or a hospice to receive the palliative care they need in their preferred place as quickly as possible.

Because of the nature of end of life care, which can last from days to years, the primary health need is reassessed every three months.

So, this means that anyone who receives a Continuing Healthcare package through the fast track tool will receive funding for their palliative care for a minimum of 12 weeks.

Palliative nursing care funding – what’s next?

CCGs commission care on behalf of those who’re eligible to receive Continuing Healthcare funding from the NHS.

Once the individual has decided on their preferred type of palliative care, Continuing Healthcare teams will work with providers and the individuals themselves to ensure that the right support packages can be organised and implemented, often with a very quick turnaround.

With the introduction of personal health budgets in April 2014, individuals and their loved ones will have a greater amount of control over who they want to provide their or their loved one’s care.



The types of palliative care available to you

Whether you're seeking end of life care for a loved one, or you're managing an end of life care case, there are a number of options available.

There are four main options available to people looking for end of life care:

- **Palliative care in hospitals**
- **Residential palliative nursing in a care home or hospice**
- **Day care at a hospice**
- **Palliative home care**

With all of these forms of care, the individual will receive pain and symptom management, and emotional support.

The environments differ quite significantly, however.

Hospital palliative nursing:

It's a form of palliative care that's often delivered over a short-term period and by specialist care teams or a single nurse – depending on the case. Palliative care teams in hospitals will monitor discharge plans and arrange for individuals to be transferred to receive palliative care in hospices, care homes or in their own home.

Palliative care in a care home:

For those who already live in a care home, remaining there to receive end of life care is a more comfortable option than having to move to a hospital ward. It's widely considered to be a calmer environment in

which to receive the medical support required.

Not all residential care homes can provide palliative care, though – only those with specially trained staff.

Hospice day care:

Hospices are similar to residential care homes in some ways. They deliver palliative nursing and rehabilitation, but people don't have to reside there permanently – they can attend for the day then return home.

Palliative care at home:

Palliative home care enables individuals to remain in their own homes to receive end of life care. Carers, specially trained in palliative nursing, will move into the home of the person they're responsible for looking after to provide round-the-clock support.

In some instances, it's also referred to as hospice at home.



The benefits of palliative care at home

The National Bereavement Survey (VOICES) – a study designed to assess the quality of end of life care – found that of the respondents that expressed a preference, 81 % stated they preferred to die in their own home⁴. And there are a number of benefits to choosing an in-home end of life care service.

Hospice at home

End of life care provided in the home is sometimes also known as *hospice at home*. With it the level of skill and support of palliative care provided within a hospice are taken and replicated within the home environment.

End of life care – in the environment they know best

Hospice at home means that they don't have to adapt to a new environment

They can receive the specialist medical support and personal care around the people and possessions that matter most to them.

It's important to remember that homes aren't just buildings – they're the locations with which many good memories can be associated. To have these reminders around during a difficult time can be a great comfort.

With hospice at home, provided by a live-in carer, your loved one can experience as little disruption to what they're used to as possible, allowing family and friends to visit on a more frequent basis.



Person-centred

It's centred entirely on the needs of the person – exactly as with live-in care.

This means that the individual needs of your loved one are all that matter.

And everything is done to ensure that they're comfortable – be it through the presence of a companion or through medical support, where necessary.



Companionship

Although carers are responsible for delivering medical support, they're also companions – someone new for your loved one to talk to, get to know and partake in activities with. The period leading up to the end of life doesn't have to mark an end to hobbies, interests and enjoyment.

As such, lots of end of life care

providers will look at the interests of individuals as well as their medical needs when assessing suitable carers.

Consistency

In any form of care – whether live-in care or end of life care – consistency is important.

Palliative care at home ensures that this consistency is maintained. It's usually

provided by one or two carers, which ensures, again, that disruption to routines is kept to a minimal level. It means that your loved one doesn't have to get used to being around multiple carers.

It's also provided within the environment an individual knows better than any other.

Complex conditions

Many palliative carers can assist with a range of complex conditions, in addition to providing the home help and personal care synonymous with live-in care. Reputable end of life care providers like Helping Hands can provide carers who are trained in ventilator, continence, gastric care, including PEG feeding, help with medication and much more.

Why use a managed palliative care service over employing a carer directly?

There are many palliative care services in the UK. There are many independent carers too. And both options may be considered.

However, it's often beneficial to go with a palliative care service that's managed – by a care provider, as opposed to employing a carer directly.

Care Quality Commission

The Care Quality Commission (CQC) monitors all care providers in the UK – whether a hospice, a residential care home or a care provider. They carry out inspections on an annual basis to determine whether the quality of care being delivered meets the high standards it has established.

Its inspection reports can be accessed through its site and

allow people to see that the service they're receiving care from meets the essential standards. Reputable managed services are registered with the CQC, whereas a directly employed carer might not be.

Personal liability cover

A managed service – whether a hospice, a residential care home or a home care provider – will have personal liability insurance in place for all of its staff. This means the care provider manages any concerns and the carer risk for you, rather than having to deal with the carer directly yourself.

Payments dealt with

Home-based palliative care providers, hospices and residential care homes deal with

the tax payments to the HMRC, and National Insurance contributions for their carers (or employees). They'll ensure that payments are made when required, and that all documentation and records are kept up-to-date.

It's a time consuming process and something you would have to take on by employing a carer directly.

Just one palliative care bill

When you directly employ a carer, there are a number of bills to contend with – paying the carer or carers on a weekly or monthly basis, reimbursing food and travel. With a managed service you can streamline the billing process.

On-going palliative care training

Lots of care providers put their carers through on-going palliative care training courses. Here, they'll learn new skills whilst continuing to develop those they already have. This allows the families of loved ones

in need of end of life care to rest assured that they're receiving the best standard of care.

Directly employed carers won't necessarily have the opportunity to undertake this level of on-going training.

Replacement palliative carers

If your loved one's palliative carer was to fall ill, with a managed service there would always be a replacement ready to step in to continue providing support – and at short notice too.

Again, this allows individuals to receive the level of care they need and their families to remain confident there'll always be someone to support.



How quickly can end of life care be arranged?

The nature of palliative care cases means that a package of care is often required at short notice.

All care providers are different, though. And, of course, this means that the time frame in which they can arrange and implement a package of end of life care will vary significantly from provider to provider.

Some care agencies, like Helping Hands, can respond to requests within hours of an initial enquiry, working with Continuing Healthcare professionals and MDTs to create a bespoke package of care, which can then be delivered straight away.

Palliative care case study

Helping Hands were contacted by the family of a gentleman with a brain tumour. He had been given a prognosis of two weeks and required 24-hour care. Together, with his family, the gentleman decided that he wanted to remain in his own home. We immediately conducted a telephone assessment to outline the support the gentleman needed, and advised a cost, which was then sent to the NHS for approval.

With the gentleman's physical care requirements and his personal interests established during the assessment, we assigned an experienced live-in carer to provide his care. Our carer worked closely with district nurses to monitor the gentleman's well-being and ensure that all his medical needs were catered for.

We worked with the gentleman's CHC team, the gentleman and his family until he passed away in his own home, around the people he loved most.



Need more information?

We hope that this guide has helped to make you more aware of the NHS support that's available for funding palliative care, the different types of end of life care available and the benefits of using a managed service over directly employing a palliative carer.

If you have any questions or you want to find out more about any aspect of Continuing Healthcare or palliative care, contact our specialist team of palliative care advisors. Our friendly team are always happy to share their expertise, provide their support, and help you with any queries you might have.

To speak to a member of Helping Hands' palliative care team, call 0808 161 1624, or visit <http://www.helpinghandshomecare.co.uk/fast-track-palliative-care.aspx>

This guide has been created by Helping Hands, a UK-based provider of nursing-led palliative care, home care, respite care and live-in care. To find out more about Helping Hands and the range of home care services it provides, go to: <http://www.helpinghandshomecare.co.uk>

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