Failing to Care – NHS continuing care campaign briefing

What is NHS continuing care?
NHS continuing care in England is a care package delivered outside of hospital for people with conditions that are complex and advanced. Care includes nursing, social care and personal care needs. It can also cover accommodation costs for those who live in a care home or hospice. NHS continuing care is arranged and funded by the NHS and is not means tested.

To be eligible for NHS continuing care, a person must be assessed as having a ‘primary health need’, have a complex medical condition and have substantial and ongoing care needs. A person has a primary health need if the main care they need is related to their health. For people with Parkinson’s, this often means being at the complex and end of life stage of Parkinson’s.

Each devolved nation has its own separate guidance and structures regarding NHS continuing care. This document focuses on NHS continuing care in England.

In 2007, the Department of Health in England published the National Framework for NHS continuing care and NHS-funded nursing care, which introduced national eligibility criteria for NHS continuing care. The framework has led to more people receiving NHS continuing care. But concerns remain over how the national criteria are adopted and interpreted within local NHS bodies.

When should an assessment for NHS continuing care be carried out?
Regulations published in 2012 set out the duties of Clinical Commissioning Groups (CCGs) and NHS England regarding NHS continuing care. These state that an assessment should be carried out:

- if someone’s physical or mental health worsens significantly
- if someone needs highly specialised nursing care
- before someone is awarded NHS-funded nursing care
- when someone is discharged from hospital if they have complex needs. This should happen before the person is assessed for help from their local authority

An individual can request an assessment independently. The NHS continuing care co-ordinator at their local Clinical Commissioning Group can arrange this. Further information should also be available from their GP.

What is the NHS continuing care assessment process?
The assessment process involves two stages. The first stage quickly captures whether a person may be eligible for NHS continuing care. The second stage is a full assessment. For people who have a rapidly deteriorating condition and are considered to be near the end of their life, senior doctors or nurses may use the Fast Track Pathway Tool to enable a speedier assessment process.
In the initial screening, a healthcare professional or social worker will assess a person’s needs using the NHS continuing care checklist. The checklist is primarily designed for healthcare professionals, but it can be a useful resource for people and their carers who are considering applying for NHS continuing care to see if they may be eligible for it.

Whatever the outcome of the screening, there should be a case review after three months to see if a person’s care needs have changed and if a full assessment is now needed. A full assessment can also be recommended without completing the checklist first.

If a person meets the criteria for funding, a full assessment is carried out by a multi-disciplinary team. The assessment is based on the following areas:

- behaviour
- cognition (thinking)
- communication
- psychological / emotional needs
- mobility
- nutrition
- continence (bladder and bowel problems)
- skin (including wounds and ulcers)
- breathing
- symptom control through drugs and medication
- altered states of consciousness

The assessment considers an individual's needs and how intense, unpredictable and complex they are in each area to establish if someone has a primary health need. Areas are marked priority, severe, high, moderate or low. If the individual attains at least a certain number of 'high' scores across certain areas NHS continuing care may be awarded. A Decision Support Tool is used to help decide this.

The multi-disciplinary team will make a recommendation about someone’s eligibility to the Clinical Commissioning Group within 28 days of the assessment being carried out.

**If I am awarded NHS continuing care, does that mean I get it for life?**

Not necessarily. Under the current system, once a person has been deemed eligible for NHS continuing care, their case is reviewed after three months and each year following that. If funding is withdrawn after a review, a person is permitted to challenge the decision.

**Is receiving NHS continuing care dependent on which setting someone lives in?**

If a person is eligible, they can receive NHS continuing care in any setting including a care home or their own home.

If someone lives in a care home and is deemed eligible for NHS continuing care, it will cover all of their care home fees, including the cost of accommodation, personal care and healthcare
costs. If NHS continuing care is provided in the person’s home, it will cover personal care and healthcare costs.

**Can I appeal a decision if my application for funding is turned down?**
Applying for NHS continuing care can be a difficult and time-consuming process. It can be helpful to approach the process with this in mind and understand which options are available if an application is refused.

To challenge a decision, a person or their representative must write to the Clinical Commissioning Group requesting a review. This request should be made within six months of receiving the initial decision. The letter should briefly explain the reasons for the challenge and should be acknowledged by the local Clinical Commissioning Group in writing within five working days.

The six-month time limit does not apply if the Clinical Commissioning Group is satisfied there were good reasons for someone missing it and it’s still possible to access relevant information and records that were used to make the original decision.

The appeal process has two stages:
- A local review process by the local Clinical Commissioning Group
- A request to NHS England who may refer the case to an independent review panel. The panel should consider the case and inform the Clinical Commissioning Group of its decision.

If a person is still unhappy with a decision they can ask for the case to be referred to the Parliamentary and Health Service Ombudsman ([www.ombudsman.org.uk](http://www.ombudsman.org.uk)), who can assess whether the correct procedure has been undertaken.

**How do personal health budgets fit in with NHS continuing care?**
Anyone already receiving NHS continuing care will have a right to ask for a personal health budget from April 2014.

A personal health budget is an amount of money to support a person’s identified health and wellbeing needs. A personal health budget gives a person more choice and flexibility to meet their needs in a way that suits them.

A personal health budget can be managed in different ways:
- a notional budget – no money changes hands, but an amount of money is made available to a person to meet their needs.
- a real budget held by a third party - once a person has discussed how the money awarded should be spent with their local NHS team, the organisation buys the care and support they have chosen.
- by a direct payment– an individual receives a cash sum and they can decide what care and support to buy with it.
If someone does not want a personal health budget, they will be able to have their care package arranged and funded by their Clinical Commissioning Group.

More information on personal health budgets can be found on the NHS England website www.personalhealthbudgets.england.nhs.uk

**Will receiving NHS continuing care affect other benefit payments?**
Receiving NHS continuing care may affect what benefits a person receives.

If a person does start receiving NHS continuing care funding, it is advisable to notify the Department for Work and Pensions. The local office should be in the phone book or on their website www.gov.uk/dwp

For more information on rights and benefits, call our dedicated employment and benefits adviser on the Parkinson’s UK helpline on 0808 800 0303 or email hello@parkinsons.org.uk

**Can I still get NHS continuing care if I live in Scotland, Wales or Northern Ireland?**

**Scotland**
In Scotland, there are separate guidelines covering applications, decision making, patient information, hospital discharge and joint working.

An independent review is currently looking at how NHS continuing care operates in Scotland. This will assess whether the guidance is being followed and if a consistent approach is being taken. It will also consider whether improvements are needed to raise awareness of NHS continuing care among professionals and the general public and consider if an independent appeals process is required. For more information contact scotland@parkinsons.org.uk

**Wales**
Guidance sets out the legal framework and the criteria for eligibility. It also outlines the processes for assessment. These range from initial overview to a comprehensive assessment, and fast track assessment for end of life care. It also provides details of the review process, dispute resolution and governance.

**Northern Ireland**
At present, Northern Ireland doesn’t have published national guidance for NHS continuing care or eligibility criteria. Decisions are made locally by the Health and Social Care Trusts. If a person feels they may qualify for continuing care, they should contact their local health and social care board for details about how to get an assessment. See www.hscni.net

**What is the Parkinson's UK position on NHS continuing care?**
Parkinson’s UK believes that NHS continuing care doesn’t currently meet the needs of people with Parkinson’s. This is due to a lack of understanding of the fluctuating, complex and progressive nature of the condition.
It is unacceptable that many people have to fight for the NHS to fulfil its obligations to provide free continuing care. We believe that fair and consistent access to NHS continuing care for people with Parkinson's must be treated as a priority by all governments.

**What is Parkinson’s UK doing to improve NHS continuing care?**

Difficulties with NHS continuing care have been a longstanding issue for people affected by Parkinson’s. It is currently one of the most common reasons people contact the Parkinson’s UK helpline and so we asked the All-Party Parliamentary Group on Parkinson’s (APPG) to conduct an inquiry into the system.

The APPG on Parkinson’s is a cross-party group of MPs and Peers with an interest in Parkinson’s. It aims to raise awareness of the condition amongst Parliamentarians and to influence legislation and policy makers in order to improve the lives of people affected by Parkinson’s.

In March 2013, the APPG launched an inquiry into NHS continuing care. After receiving evidence from 12 organisations and 41 people affected by Parkinson’s, the report was published in November 2013. It found that NHS continuing care in England is currently not fit for purpose and abandons people when they are at their most vulnerable. It makes a number of recommendations on how the system should be improved.

The APPG inquiry into NHS continuing care revealed a number of fundamental problems with the system. Most shockingly, it was discovered that owing to a lengthy process of application, appeal and review, some people with Parkinson’s are dying whilst waiting for the NHS to make a decision on whether they are eligible.

In November 2013, Parkinson’s UK launched the Failing to Care campaign based on the recommendations in the report because we believe that NHS continuing care in England must change.

Parkinson’s UK wants NHS England to be accountable for continuing care and are calling on the Government to urgently improve the system by taking the following actions:

- Understand and meet the demand for these services by collecting condition-specific data - at every stage of the process - for those applying for continuing care.
- End uncertainty for those involved in assessments by establishing an improved national framework with clear processes, guidance and timelines for decision making, that are applied by Clinical Commissioning Groups who are held to account by NHS England for their performance.
- Implement an assessment process that reflects the needs of people with complex and fluctuating conditions, including assessments that involve healthcare professionals with expertise in that condition.
- Give vulnerable individuals a voice by developing a truly independent review process to consider complaints or appeals against decisions and, if these decisions are upheld, that care costs incurred are repaid in full.
• Reduce anxiety for those worried their care will be taken away with an agreement that applicants with a progressive condition, or one that will never change, should not be continually reassessed for eligibility.
• Ensure sick and vulnerable people are able to navigate the difficult assessment process by giving them the right to experienced, independent support for everyone applying for continuing care.

As part of the Failing to Care campaign, Parkinson’s UK, alongside other charities, will be campaigning throughout 2014 to ensure the Government and NHS act on all of our recommendations.

How can I get involved with the Failing to Care campaign?
You can help with the campaign by sending an email to your MP asking them to demand that Secretary of State for Health, Jeremy Hunt MP, takes up our recommendations for improving NHS continuing care. To email your MP, use our simple form on our Failing to Care campaign page parkinsons.org.uk/failingtocare

For more information
• Alzheimer’s Society has a number of useful documents on NHS continuing care and has produced a booklet ‘When does the NHS pay for care?’, which explains what NHS continuing healthcare is, how to get an assessment and how to complain if you think you have been wrongly charged for care.
• Age UK also has an in-depth factsheet on NHS continuing care.
• The Spinal Injuries Association also has a detailed information pack on NHS continuing care.

Any questions?
Our helpline 0808 800 0303 can answer questions you may have about continuing care. They can also put you in touch with one of our local information and support workers, who provide one-to-one information and support to anyone affected by Parkinson’s. They can also provide links to local groups and services. You can find out more about the service at parkinsons.org.uk/isw

For more information on our Failing to Care campaign to improve NHS continuing care please visit parkinsons.org.uk/failingtocare

You can also contact Leo Watson, Policy and Campaigns Adviser on 020 7963 9322 or email lwatson@parkinsons.org.uk if you would like to share your experiences or find out more about the campaign.