

Parkinson's UK policy statement NHS continuing care

"I was stunned when they withdrew her continuing care after over four years. Despite having a degenerative condition, being under seven specialists, and in need of special equipment and nursing, I was told as a parting shot at the Tribunal that the more ill you become it is sometimes harder to qualify for continuing healthcare because the risks may be less. The PCT will not let anyone get in the way of protecting their budget."

Daughter of person with Parkinson's

What we believe

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.

This means raising public awareness of rights and criteria for accessing NHS continuing care, and designing a system that takes account of the full symptoms and fluctuations of Parkinson's, involving the person with Parkinson's, carers and professionals who know the person best. It means providing timely and well justified decisions and prompt and accessible rights of appeal, and it should enable people to choose where they receive NHS continuing care, be it in residential care or at home.

Why we believe this

Continuing care is professional care given to meet the physical or mental health needs of adults with a disability, injury or illness over an extended period of time. NHS continuing care means a package of care that is arranged and funded by the NHS and is free of charge to the person receiving the care. It can be provided in residential homes, hospital, hospices or in a person's own home. The decision for eligibility rests not on the condition but on whether the need for care is primarily due to health needs – often referred to as a 'primary health need'.¹

The complex health needs that people with advanced Parkinson's have mean that some people are likely to meet the criteria. Motor symptoms such as tremor, muscle rigidity and slowness of movement and commonly occurring non-motor symptoms including difficulties with balance, incontinence, difficulties swallowing, pain and mental health problems such as dementia and hallucination may be of such a nature to indicate a primary health need. However there are a number of barriers which exist in accessing NHS continuing care.

Lack of public awareness

The lack of information on and awareness of rights to NHS continuing care means many people may be wrongly paying for their care.

¹ This is a definition used in national guidance for England and Wales. Scotland's national guidance uses "ongoing health needs". Northern Ireland does not have any national guidance at present and it is up to local Health and Social Care Trusts to decide on the criteria. See **Appendix 1** for more information.

Even when found eligible, some people find they are told they must move to residential care, when staying in their home could be an option. This is particularly true when someone has no close family or friends to help them express their wishes.

The information about NHS continuing care should be much more readily available from health and social care professionals, who should be open about the process. Sometimes neither the individual nor their family are told they have been screened for eligibility or find they have to trigger the process by requesting assessment. Access to independent advocacy is essential, and can help people navigate the system. Decisions must be clear, with detailed reasons, and made fully available to the person and their representatives.

Assessing Parkinson's

There is a variation in what people experience in terms of assessments and eligibility, as whatever guidance and criteria exists nationally, these are still open to local assessor interpretation and reasoning. This is not helped by national support tools that exist to help “score” someone's health needs, which are not sophisticated enough for a condition like Parkinson's and the side effects of Parkinson's medication.

There is also a lack of awareness of Parkinson's among some assessors. People with Parkinson's and their families report inadequate periods of time for the assessment, resulting in a false impression of the person. Judgments can be made on nursing home or hospital notes that do not adequately reflect the person's symptoms and fluctuations.

It is important to encourage people applying for NHS continuing care to document carefully all the health interventions needed by a person with advanced Parkinson's over a period of time. There should be an obligation on assessors to seek out and give much more weight to the evidence of specialists, Parkinson's nurses and other professionals who know the person's health needs well. Decision tools should be redesigned to establish a much fuller picture of someone's health needs and the complexity of a condition such as Parkinson's.

Bureaucracy

Despite the existence of guidance from government, there has been criticism of both decision making, review and appeal processes locally. The “unspoken” financial costs mean there is little incentive for the NHS to make timely decisions once someone has applied for NHS continuing care. If their case is rejected, the appeals and tribunal processes can be very daunting and adversarial at a time when a person may be at their most vulnerable, and full of delays. Reports are that reviews will often be instigated not because of a change in health needs but because of budgets.² There may be a reluctance to increase someone's package of support at review, or people being told that their needs no longer meet the criteria although their condition is advancing and deteriorating.

Governments should address these delaying tactics by establishing a timescale for decision making when someone makes an application, and ensuring that the NHS body funds the care

² For example, see criticism by an independent report on NHS Devon withdrawing continuing care funding to nearly half of 300 people eligible for it in 2009. <http://www.thisisexeter.co.uk/news/article-1296725-detail/article.html>

package from the date of someone's initial claim. It should also be the case that there should be no need to repeatedly review the eligibility of someone with advanced Parkinson's for NHS continuing care as the condition is degenerative and deteriorating at this stage (although their support package may need to increase to reflect increased complexity of health needs so regular review of the package will be essential).

Lack of choice

Although NHS continuing care is free at the point of delivery, it does not necessarily give people the freedom and choice available through the social care system. For example, in residential care, local authority funded clients have a right to choose their care home accommodation and can use their own funds to “top up” their care package (although these are not without issues). These rights do not apply to residents whose care is fully funded by NHS continuing care although people can express a preference for a certain home. Since it is illegal to pay a “top up” fee under NHS continuing care (as the NHS is free at the point of delivery) the price the local NHS body is prepared to pay for a placement limits the number of residential homes that will accept the individual.

And unlike social care where direct payments are widespread and enable people to remain in their own home, with their choice of support, there is no right to direct payments or personal budgets under the NHS. If someone using these becomes eligible for NHS continuing care they may lose their choice of support in their own home.

Governments should address these issues so there is an inbuilt right to choice available to people using the NHS continuing care system.

Cost shunting

Services provided by the NHS are free at the point of delivery whereas those arranged by social services are means tested. The outcome of any decision as to who has overall responsibility for the care package can have significant financial consequences for the person with Parkinson's and their family.³ If a person is deemed to have social care needs, they may have to sell their home to fund their care. This can seem extremely unfair.

While eligibility decisions should be independent of budgetary constraints within the NHS, local NHS bodies have been subject to a number of legal challenges from people who were wrongly told they were ineligible.

In effect the boundaries between health and social care appear to have been gradually redrawn, making it much harder to qualify for free healthcare.⁴ This leaves many people with complex health needs being cared for within a social care system that often lacks the resources or expert staffing to manage these needs, and places added pressure on informal carers. All governments need to address these issues by reviewing the situation regarding NHS continuing care in each country and taking firm action so that the NHS meets its

³ Note that free personal and nursing care in Scotland for those over 65 may mean less of a financial impact on those who are eligible for social care, as the state is contributing towards people's care costs in nursing homes, care homes and in their own homes.

⁴ For example, see chairman of Health Select Committee comments to BBC News 29 September 2010 *Vulnerable elderly 'forced to pay for medical care'*.

obligations. This could include introducing independent decision making, to avoid judgments being clouded by budgetary considerations.

What's the evidence?

Unfortunately there is little data on the number of people with specific conditions who are in receipt of NHS continuing care, so there is little information on the numbers of people with Parkinson's who receive it. Anecdotally, calls to the Parkinson's helpline increase when there are media reports on access to NHS continuing care, which indicates many people are not being told about the possibilities of a continuing care assessment.

Since the introduction of the national framework in England, the number of people receiving NHS continuing care has increased from 27,822 at the end of September 2007 to 50,424 at the end of March 2010. It is encouraging that more people are receiving NHS continuing care but concerns remain as the interpretation of national criteria remains with local NHS bodies and there is a continued absence of national criteria in Northern Ireland. Department of Health statistics⁵ reveal a variation in the number of people receiving NHS continuing care across PCTs that have similar demographics in England.

What Parkinson's UK is doing

We are working to ensure that people are aware of their rights to NHS continuing care through our information resources, advisory services and regional teams. We also train professionals working with people with Parkinson's so they are better educated about the condition. We also campaign for improvements to the way social care is funded, and fair access to care services.

Acknowledgement

We are grateful for the advice and guidance of our Policy Panel in shaping this position paper on NHS continuing care. The Policy Panel consists of people with experience of Parkinson's who meet on a regular basis to help guide the charity's position on a range of policy issues.

Further information

Please contact the Social Policy and Campaigns team. Tel: 020 7963 9307 or email: campaigns@parkinsons.org.uk

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⁵ Table showing numbers of people receiving continuing care, Department of Health (2010)
www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_116297.xls

Appendix 1: National guidance on NHS continuing care

England

A National Framework for NHS continuing care was developed in 2007 (and revised in 2009) in England.⁶ The intention of national guidance has been to clarify the criteria. England has published accompanying decision tools to introduce more consistency of decision making in the NHS. The new framework contains a checklist tool that screens those going forward for a full eligibility assessment, a full decision support tool to be used as part of a comprehensive multidisciplinary assessment of needs⁷, a “fast track” pathway tool where individuals have a rapidly deteriorating condition and need end of life care, the processes for review, dispute resolution and governance.

Scotland

Scotland published new guidance in 2008. In Scotland the guidance sets out the processes and principles for eligibility applications, decision making, patient information, hospital discharge and joint working. Scotland announced it would also develop and pilot an additional assessment tool to promote consistency in how the criteria are applied across Scotland but this has not been published as of 2010.⁸

Wales

A new framework was published in 2010. The guidance sets out the legal framework and clarifies criteria for eligibility. It also sets out the processes for assessment ranging from initial overview to a comprehensive assessment using a decision support tool with detailed criteria, and fast track assessment for end of life care. It also sets out the processes for review, dispute resolution and governance.⁹

Northern Ireland

Northern Ireland has not published national guidance or criteria at present. Decisions are made locally by the Health and Social Care Trusts.

⁶ Department of Health *National Framework for NHS continuing healthcare and NHS-funded nursing care* (2009) www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_103162

⁷ Assessments can be done by a doctor, nurse, other qualified healthcare professional or social worker but the full assessment will always require input from more than one professional.

⁸ Scottish Government *NHS Continuing Healthcare* (2008) www.sehd.scot.nhs.uk/mels/CEL2008_06.pdf

⁹ Welsh Assembly Government *Continuing NHS Healthcare: The National Framework for Implementation in Wales* (2010) <http://wales.gov.uk/docs/dhss/publications/100614chcframeworken.pdf>