

FAILING TO CARE:

NHS continuing care in England

Executive summary and key recommendations

“Like so many others of my generation we have worked for more than 50 years without claiming any welfare support. It came as an unwelcome blow when my wife, having suffered for 30 years with the loss of health and gradual decline brought on by Parkinson’s, was informed that just as the point is reached where the impact of her illness and the level of total care needed are close to their peak, the NHS could not provide it free of charge.”¹

NHS continuing care is an NHS funding package designed to provide free health care for all those who are eligible. Yet the system is shrouded in mystery and disarray, leaving thousands of vulnerable and sick people with no choice but to pick up the cost of specialised care they cannot live without – with those living with long-term, degenerative conditions particularly at risk.

In the wake of growing concerns that NHS continuing care is far from fit-for-purpose, Parkinson’s UK, alongside the All Party Parliamentary Group on Parkinson’s, conducted the first-ever Inquiry into the ailing system. It found:

- due to a lengthy process, people with Parkinson’s are dying whilst waiting for their health board to make a decision on whether they are eligible
- 59 per cent of assessments did not involve a professional with specialist expertise or knowledge in the condition – leading to inaccurate and incorrect decisions on funding
- all of the health and social care professionals we spoke to admitted the system is so complex they have difficulty following the correct process

- 40 per cent of people going through the assessment process reported experiencing a lack of empathy and transparency from professionals, in the decision making process and in appealing against a decision
- 24 per cent of people with Parkinson’s were continually reassessed, despite living with a progressive condition
- in 21 per cent of cases examined, there were clear examples of existing national guidance not being followed either in the length of assessment or in how the decision is made, with no repercussions for breaching these guidelines
- a lack of local NHS’ performance data meant that the Department of Health is unable to tell if and where issues are occurring. The lack of monitoring and enforcement also means that they are not taking action to resolve them

Current changes in health and social care provision mean the government must act now to end the care crisis and ensure that NHS continuing care finally supports those who need it most.

Parkinson's UK wants NHS England to be accountable for NHS continuing care and is calling on the Government to urgently redevelop the system.

To end the chaos, by the end of 2014 NHS England must:

- understand and meet the demand for these services by collecting condition specific data, at every stage of the process for those applying for NHS continuing care
- end uncertainty for those involved in assessments by establishing an improved national framework with clear processes, guidance and timelines for decision making. These should be 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, ensure 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 NHS continuing care

Foreword

As someone whose father had Parkinson's I am aware that having the right support from services is vital at what can be a difficult time for people. However, I was shocked to hear that people with Parkinson's and other conditions are being let down when they need the support provided by NHS continuing care.

As Chair of the All Party Parliamentary Group on Parkinson's I was concerned to learn that NHS continuing care is one of the main reasons that people contacted the Parkinson's UK helpline. I learned too that others with complex health needs also experience similar difficulties with the system, often leaving them without the support they need, or having to pay high costs for care that should be free.

This Inquiry has looked into the NHS continuing care system in England and identified clear issues that cause difficulties for people attempting to claim the funding. It makes robust recommendations for the Department of Health and NHS England to overcome these issues and help people who are eligible for NHS continuing care to be awarded this funding as promptly as possible, so that they can receive the care and support they need without worrying about the costs.

I would like to thank all of those who submitted written evidence to the Inquiry, and all of the witnesses who came to Parliament to speak in front of the Inquiry panel. In particular, the personal accounts of trying to navigate the NHS continuing care system were incredibly moving and certainly helped the panel to understand the difficulties that they faced.

I trust this report will help Parkinson's UK in their work of campaigning for improvements in NHS continuing care, and that those responsible for the NHS continuing care systems in the UK will take on these recommendations to ensure people get the support they need.

Baroness Gale
Chair, All Party Parliamentary Group on Parkinson's

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About Parkinson's

Parkinson's is a progressive neurological condition. People with Parkinson's don't have enough of a chemical called dopamine because some nerve cells in their brain have died.

Without dopamine people can find that their movements become slower so it takes longer to do things. The loss of nerve cells in the brain causes the symptoms of Parkinson's to appear.

There's currently no cure for Parkinson's and we don't yet know why people get the condition. Parkinson's doesn't directly cause people to die, but symptoms do get worse over time.

One person in every 500 has Parkinson's. That's about 127,000 people in the UK. Most people who get Parkinson's are aged 50 or over but younger people can get it too. One in 20 is under the age of 40.

The main symptoms of Parkinson's are tremor, rigidity and slowness of movement. As well as affecting movement, people with Parkinson's can find that other issues, such as tiredness, pain, depression and constipation, can have an impact on their day-to-day lives. The symptoms someone has and how quickly the condition develops will differ from one person to the next. The symptoms can be controlled using a combination of drugs, therapies and, occasionally surgery.

As Parkinson's progresses, an increased amount of care and support may be required, although many people maintain a good quality of life with limited care or treatment. The complex health needs that people with advanced Parkinson's have mean that some people are likely to meet the criteria for NHS continuing care. Motor symptoms such as tremor, muscle rigidity and slowness of movement and commonly occurring non-motor symptoms, including difficulties with balance, incontinence, swallowing, pain and mental health problems, such as dementia and hallucinations, may be of such a nature to indicate a primary health need.

About the APPG on Parkinson's

The All Party Parliamentary Group (APPG) on Parkinson's was established in June 2008. It is a cross-party group of MPs and Peers with an interest in Parkinson's.

The aim of the APPG is 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.

The Group is chaired by Baroness Gale. It aims to meet several times each year, and to focus upon specific issues that are of importance to people with Parkinson's, their families and carers.

Parkinson's UK acts as the Secretariat to the Group and provides administrative support to the Group.

Part 1: Background

Background

NHS continuing care is defined as 'free care outside of hospital that is arranged and funded by the NHS'.² It can also be referred to as NHS Continuing Healthcare or fully funded NHS care. For the purposes of clarity, it will be referred to as NHS continuing care throughout this report.

NHS continuing care can be provided in any setting, including a care home, hospice or the home of the patient. If someone living in a care home 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 patient's home, it will cover personal care and healthcare costs. To be eligible for NHS continuing care, the patient must be assessed as having what is deemed a 'primary health need and have a complex medical as well as and substantial and ongoing care needs.

People affected by Parkinson's tend to be eligible for NHS continuing care when their condition has progressed to an advanced and complex stage. They may have also developed dementia as part of their Parkinson's.

Following issues raised by people affected by Parkinson's who had experience of the system, Parkinson's UK was concerned that NHS continuing care was not operating effectively. The charity was also aware of other organisations that had similar concerns about the system failing to fully support their own beneficiaries with other conditions and needs.

It was felt that, due to the current changes to both the health and social care systems in England, it would be an opportune moment to assess any issues that existed with NHS continuing care and how it was being implemented. By considering the current challenges and devising solutions to improve the situation for those seeking NHS continuing care funding, it would then be possible to influence the evolution of both the health and social care systems and use the current opportunity of the Care Bill to improve matters.

Difficulties with NHS continuing care has been a long-standing issue for people affected by Parkinson's. It is currently one of the most common reasons people contact the Parkinson's UK helpline. A number of reasons for these difficulties have been cited, but most people reported difficulties due to a lack of understanding of the fluctuating, complex and progressive nature of Parkinson's. It is believed by the charity that NHS continuing care is not currently meeting the needs of people affected by Parkinson's in an appropriate, consistent and timely manner across the UK.

People considered eligible for NHS continuing care tend to have severe health needs. For people with Parkinson's, this often means being at the complex and end of life stage of Parkinson's – where they are very vulnerable

and may be experiencing dementia symptoms and other cognitive issues. Due to the nature of Parkinson's, people with the condition who are eligible for NHS continuing care² are often not in a position to make the application independently. It is often made by their families on their behalf.

The process these families go through to obtain NHS continuing care for their relatives tends to be complicated and stressful for all concerned. Parkinson's UK believes that it is vital that patients eligible for NHS continuing care should be able to claim the funding as and when they need it. The charity believes that it is "unacceptable that many people have to fight for the NHS to fulfil its obligations to provide free continuing care"³ and has called on all UK governments to ensure there is fair and consistent access to NHS continuing care.

There have been other instances where NHS continuing care has been investigated by various bodies. Although the investigations were carried out a number of years ago, (in a different NHS environment), a number of clear themes have emerged identifying fundamental difficulties with NHS continuing care.

In February 2003, the Health Service Ombudsman published a report into NHS continuing care, partly prompted by the level of complaints they had been investigating over the previous 18 months. The complaints had arisen due to a number of issues, which the Ombudsman defined as "informing and involving patients and their relatives; developing eligibility criteria for NHS-funded care in line with guidance issued in 1995; reviewing eligibility criteria in light of the Coughlan judgement (July 1999); the national framework for NHS funded care; assessment against criteria".⁴ The Ombudsman felt that these issues had arisen due to "weaknesses in the Department's [of Health] guidance."⁵

The Ombudsman made a number of recommendations, including calling on Strategic Health Authorities and Primary Care Trusts (PCTs) to take account of Department of Health guidance, the Coughlan judgement and the report when reviewing eligibility criteria. The report also encouraged these bodies to “remedy any consequent financial injustice to patients, where the criteria, or the way they were applied, were not clearly appropriate or fair.”⁶ The Ombudsman also called on the Department of Health to monitor authorities’ and PCT performances, to clarify the guidance on when the NHS should fund care and to take a more proactive approach to checking the criteria used followed their guidance.

The Government responded to this by commissioning an independent review into NHS continuing care and subsequently announced in December 2004 that the government would develop what became the national framework for NHS continuing care. The then Parliamentary Under-Secretary of State for Health, Stephen Ladyman MP, confirmed that the new criteria would “improve consistency and ease of understanding ... all the current criteria are fair and legal. It will however make the process easier to understand for practitioners and patients alike.”⁷

The Commons Health Select Committee then held an inquiry into the issue and published a report in April 2005. The report contained recommendations for the National Framework for NHS continuing care, which was in the process of being developed. The committee’s report described NHS continuing care as a “bewildering funding system which is little understood even by those who administer it.”⁸ While the report largely focused on the need for national eligibility criteria, it also commented on other issues. The ongoing difficulties caused by the divide between health and social care were cited, with the committee recommending “that the Government removes the structural division between health and social care”⁹ to alleviate these difficulties. The report also

insisted that the national criteria being drawn up should ensure that mental health and psychological needs carried equal weight to that of physical needs, to avoid disadvantaging people with dementia and “other progressive and degenerative conditions, including motor neurone disease and Parkinson’s.”¹⁰

The report also noted that the Coughlan case would not be eligible for NHS continuing care under the then-current criteria. The report expressed concern that many people did not undergo assessments for NHS continuing care because they were unaware of the system and called on the government to legislate for a nominated individual in all care settings “whose responsibility it is to proactively identify all those who may need a continuing care assessment and notify the appropriate PCT, which should have a duty to arrange for an assessment (or re-assessment) within a specified timescale.”¹¹

The report further recommended thorough training for staff carrying out assessments for NHS continuing care and a standard national assessment methodology. The concerns of the Ombudsman were also repeated in the recommendations that called for service users and families to be kept better informed and for the government to monitor the implementation of the new criteria.

Another key issue raised by the Commons Health Select Committee was the incidence of individuals being denied NHS continuing care due to financial pressures within PCTs. The report saw the then PCT review panels acting as “a gatekeeping function to manage demand on PCT financial resources. Eligibility criteria and related assessments must be based on the needs of the individual, and must not take account of the financial consequences.”¹²

The government subsequently published its response to the inquiry, in which it committed to producing guidance for assessors for implementing and applying the national

eligibility criteria. That, combined with other commitments, aimed to “raise the profile of continuing care within the NHS and aims to improve the public’s understanding of eligibility, and of the assessment process.”¹³

NHS continuing care across the UK

NHS continuing care is in the remit of each of the four UK countries’ own health departments. Although the process for applying for NHS continuing care is broadly similar, the detail varies due to the differences in the health systems across the countries and there are variations in how the system is implemented. As a result, there are significant differences in the NHS continuing care systems across the UK.

England

In England, criteria for NHS continuing care were first introduced by the Department of Health in 1995.¹⁴

A National Framework for NHS continuing care was developed in 2007 and has been revised on subsequent occasions, most recently in November 2012.¹⁵ The intention of creating national guidance had been to clarify the criteria for eligibility. England has also published accompanying decision tools to introduce greater consistency of decision making throughout the NHS. As of 31 March 2012, 56,411 people in England¹⁶ were listed as claiming NHS continuing care.

The framework contains a checklist tool to identify who should go for a full eligibility assessment, a full decision support tool to be used as part of a comprehensive multidisciplinary assessment of needs,¹⁷ a ‘fast-track’ pathway tool where individuals have a rapidly deteriorating condition and need end of life care, and also the processes for review, dispute resolution and governance.

For someone to qualify for NHS continuing care in England, they must undergo an assessment by a multidisciplinary team that considers the following areas:

- behaviour
- cognition
- communication
- psychological / emotional needs
- mobility
- nutrition
- continence
- skin (including wounds and ulcers)
- breathing
- symptom control through drug therapies and medication
- altered states of consciousness

The assessment considers the nature of an individual's needs and how intense, unpredictable and complex they are in each area, in order to establish if someone has a "primary health need." In England, areas are marked priority, severe, high, moderate or low. If the individual attains at least a certain number of 'high' scores across certain areas, as suggested by the Department of Health in its guidance on the Decision Support Tool (DST),¹⁸ NHS continuing care may be awarded, although the DST encourages assessors to look at the overall totality of needs. The case is then regularly reviewed. In some situations, such as the individual entering the end of their life, the assessment can be fast-tracked to ensure a care package is implemented as soon as possible.

If care is not awarded, it is possible to appeal against the decision. This varies according to each country, but in England, this begins with the local dispute resolution procedure and ultimately is referred to the Parliamentary Health Service Ombudsman.

The system for NHS continuing care has undergone several changes over the years. The most significant arose from a legal challenge made in 1999 when Pamela Coughlan went to court after the NHS attempted to move her from an NHS-funded residential facility to a social services-funded facility. They also asked her to pay the fees for that care. The case was referred to the Court of Appeal.

The court ruled that the NHS should continue to fund Ms Coughlan's care. In its ruling, the court judged that a local authority could only provide for the health needs of an individual when it is incidental to the needs provided by the local authority.

The court ruled that Ms Coughlan's healthcare needs were of a significant level that they were beyond that of what a local authority could reasonably be expected to provide and were therefore the responsibility of the NHS. Pamela Coughlan's case is significant because her identified health needs were not that substantial – although she was a tetraplegic, she could use a computer with voice technology and an electric wheelchair independently. This landmark ruling led to the development of the National Framework for continuing care in England and the additional Decision Support Tool to try to ensure that individuals with a primary health need could be assessed for eligibility for NHS continuing care.¹⁹

It is important to note that 'primary health need' is a concept developed by the Secretary of State for Health, as indicative of the 'quality and quantity' test under the Coughlan case, and the term 'primary health need' does not appear, nor is defined, in primary legislation.

Ms Coughlan's needs were described as being of a quality and quantity beyond that which social services could lawfully provide for. The quality test is whether the nursing services are of a nature that an authority whose primary responsibility it is to provide social services can be expected to provide.

The quantity test is whether the nursing services are merely incidental or ancillary to the provision of the accommodation which a local authority is under a duty to provide. It was felt that the services Ms Coughlan needed had to be provided by the NHS. Therefore, despite her relatively low level of needs, the court ruled that Ms Coughlan should receive funding from the NHS (free at the point of use), rather than social services (paid for at the point of use).

Since then, there have been a number of other challenges, such as rulings from the Parliamentary and Health Service Ombudsman, which have been used in support of cases of claiming NHS continuing care. On April 1 2013, the structure of the NHS in England was changed as the Health and Social Care Act came into effect.

The main impact on NHS continuing care is that it is now arranged by Clinical Commissioning Groups (CCGs) rather than Primary Care Trusts (PCTs). It remains to be seen what happens to NHS continuing care under the new system. However, given the costs associated with funding NHS continuing care, and given that CCGs cover a smaller population size than PCTs, NHS continuing care may create a proportionately larger burden on CCG budgets.

Looking ahead, it is vital that there is a distinction between health and social care needs, as social care is means tested and health is free at the point of delivery in England. The Care Bill, which is currently going through Parliament at the time of writing, has presented a clear opportunity to clarify the boundary between health and social care and we are delighted that the 'quality and quantity test' has been enshrined in legislation.

The Joint Committee on the Draft Care and Support Bill recommended that a care and support tribunal should be established to resolve disputes. It was thought that the changes to the social care system were likely to create an increase in the number of disputes over

who was responsible for paying for care. The committee further recommended that this tribunal should be given responsibility for resolving disputes on NHS continuing care.¹⁹

Scotland

Scotland has proportionately a much lower level of people claiming NHS continuing care than in England, with 2,006 people receiving NHS continuing care in Scotland²⁰, compared with 56,411 people in England²¹ as of 31 March 31 2012.

Although the population in Scotland is smaller, this is a disproportionately smaller amount and may be attributed to the differences in the funding for social care systems. In Scotland, personal care is provided free of charge to certain groups, including the over-65s. However, this is capped at £166 per week.²² It is also worth highlighting that this free care only covers personal and nursing care. Claimants are still required to cover other costs such as costs for bed and board for those in residential care.

This has resulted in people who have failed the assessment process for NHS continuing care having to 'top-up' the costs of care, which in cases of caring for people with Parkinson's, can be quite substantial and likely to exceed the cap. A recent case detailed spending £32,000 in 16 months to provide care for someone with Parkinson's.²³ It has also been noted that the number of people claiming NHS continuing care in Scotland has continued to decline over recent years – falling by 20 per cent between 2010 and 2012.

The Scottish Government published guidance in 2008 to set out the processes and principles for eligibility applications, decision making, patient information, hospital discharge and joint working. It was also announced that the Scottish Government would develop and pilot

an additional assessment tool to promote consistency in how the criteria are applied across Scotland²⁴ but at the time of writing, this is yet to appear.

There is the additional complication that, due to the lack of an independent appeals system, if patients in Scotland feel their case has not been fairly heard, they cannot refer the case any higher and cannot request the case be re-assessed.

In June 2013, there was a news story about people in Scotland paying for costs of care when they should not have, based on a case of a woman being refused NHS continuing care despite being severely brain damaged after a stroke.²⁵

The reaction to this story prompted Scottish Health Secretary Alex Neil to pledge that in every case where it was felt that the person should have been eligible for NHS continuing care, this would be investigated and all monies would be fully reimbursed.²⁶

The Scottish Government then also launched an independent review into NHS continuing care²⁷ to be led by Ian Anderson, previously past president of the Royal College of Physicians and Surgeons of Glasgow. The review is due to report back to Alex Neil later in 2013.

Submissions were sent in to the inquiry, which detailed difficulties with claiming NHS continuing care in Scotland.

Wales

In Wales, a new framework for NHS continuing care was published in 2010 and is due to be reviewed in the autumn of 2013. The guidance set out the legal framework and clarifies criteria for eligibility. It also set out the processes for assessment, ranging from an initial overview to a comprehensive assessment using a decision support tool with detailed criteria, and the option for a fast-track assessment for end of life care. It had also set out the processes for review, dispute resolution and governance.²⁸ The number of individuals claiming NHS continuing care in Wales is not currently recorded.

It has been noted that the Welsh framework has altered the scorings for the cognition domain so that the maximum that can be awarded is 'high'. As it is still necessary to score 'severe' in two separate domains in order to qualify for NHS continuing care, this change makes it harder for individuals in Wales to be successfully awarded the funding.

During the oral evidence given by the Alzheimer's Society, it was noted that one health board is currently processing all of the appeals in Wales, causing significant delays to cases being referred to the Public Service Ombudsman for Wales – the final stage of appeal. One witness described the current appeals process in Wales as a "shambles". Following a recent case, the Ombudsman raised concerns about a lack of guidance on processing retrospective applications in Wales and called on the Welsh Assembly Government to issue guidance on this issue and to ensure health boards complied with all guidance and legislative requirements.²⁹

During the call for evidence as part of this inquiry, submissions were received from individuals in Wales who had experienced difficulties in claiming NHS continuing care.

Northern Ireland

In Northern Ireland, there are significant differences with NHS continuing care, as health and social care is provided jointly via six Health and Social Care Trusts. However, as some social care costs can still be paid by the individual, NHS continuing care is still available and funded via the health service. The number of individuals claiming NHS continuing care in Northern Ireland is not recorded.

At present, there is no published national guidance or criteria in Northern Ireland. Decisions are made locally by the health and social care trusts and individuals are required to meet the eligibility criteria set by each trust.

From initial research, it was queried whether NHS continuing care was even used in Northern Ireland, due to the joint nature of health and social care provision. However, during the Inquiry's call for evidence, a submission was received detailing difficulties with claiming NHS continuing care in Northern Ireland.

Part 2: Inquiry findings

About the Inquiry

Since these reports were published, there has been no further detailed investigations into the system for NHS continuing care in England. There has been some additional work on retrospective claims for funding and it has been discussed as part of the work around changes to the social care system, but there has been no significant discussion of note about the system as a whole.

Parkinson's UK asked the APPG on Parkinson's to conduct the Inquiry on the charity's behalf. It was agreed to limit the scope of the Inquiry to the NHS continuing care system in England. It was also agreed not to include NHS funded nursing care³⁰ in the scope of the Inquiry. However, details about the systems in the

other three UK countries is included for context and it is worth noting that people came forward to give evidence from all of the UK countries, expressing their concerns about their particular system for NHS continuing care.

The Inquiry was formally launched in March 2013 with a call for written evidence. A series of four oral evidence sessions were then held at the Houses of Parliament in June and July 2013 to gain more detail from 15 witnesses.

This Inquiry seeks to identify where challenges exist with NHS continuing care and what could be done to eliminate them to ensure individuals who are eligible for NHS continuing care receive it promptly and to a standard that meets their needs.

Failing to care – people's experiences of NHS continuing care

The evidence received by the Inquiry, included many individuals and organisational experiences of claiming and working on NHS continuing care. Although there were some positive experiences, they were very much in the minority.³¹ Most of the individual responses detailed negative experiences of NHS continuing care. From the responses the Inquiry received from twelve organisations, virtually all of them expressed concerns about the process and felt that it was not appropriately supporting people who may need NHS continuing care. This was also an opinion expressed by many of the health and social care professionals who submitted evidence to the Inquiry, either individually or via an organisation.

“The process is intimidating, humiliating, unfriendly, exhausting, degrading, aggressive, frustrating and also it is adversarial. These are terms that I have written down that patients, relatives and even CHC assessors have used themselves.”³²

Karen Guy, Parkinson’s Disease Nurse Specialist

“Only a minority of people are successful in claiming NHS funding for their continuing care needs ... it is clear that most people’s care needs are not being met by NHS continuing care funding.”³³

Parliamentary and Health Service Ombudsman

A number of submissions were made to the Inquiry anonymously for that specific reason and it is likely that others may have decided not to come forward at all. It is very likely that some individuals experiencing difficulties with NHS continuing care may feel concerned about potentially endangering their cases by speaking out and that the issue is more widespread than can be determined from the evidence.

Many of the individual submissions detailing difficulties with NHS continuing care concerned people with either Parkinson’s dementia or dementia with Lewy Bodies. It is possible that a dementia diagnosis made it more likely for there to be complications with the process.

This reflects the typical sentiments expressed by the vast majority of those who submitted comments about NHS continuing care. A number of submissions were sent in anonymously as individuals were concerned that by talking about their experiences of NHS continuing care, it could either prejudice an ongoing appeal or impact on their relative’s current funding status.

Throughout the process of the Inquiry, a number of common concerns with NHS continuing care were clearly identified and are detailed below.

Lack of knowledge and information

One of the clearest issues that came through as part of the Inquiry was the lack of knowledge about NHS continuing care – both from professionals and service users alike. Lack of knowledge can be split into two areas – a lack of awareness and a lack of understanding about NHS continuing care.

From the submissions we received from individuals, the vast majority of them had never heard of NHS continuing care before they first encountered it. As it appears that it is not a particularly well-publicised, it is not something that occurs to individuals and their families to pursue. Many of the submissions we received referred to finding out about the possibility of applying for NHS continuing care by chance, due to a conversation with a member of hospital staff or social worker. This was particularly relevant when it came to the assessment process for the individuals and their families. The Spinal Injuries Association felt that this lack of knowledge severely disadvantaged individuals and their families:

“People are assessed and they are not told in detail what they are going to be assessed against and what they have to do to qualify for continuing health care. So, essentially, you are going through an assessment process without understanding the process and without understanding the pass mark.”³⁴

The submissions also detailed a lack of understanding by the health and social care professionals working on NHS continuing care.

Specifically, there seemed to be the belief that individuals were only eligible if they were extremely ill or at the end of their lives. Several people recollected being told that in order to be awarded NHS continuing care, the individual had to be 'practically dead'.³⁵ Although there is a 'fast-track' option for individuals in an end-of-life phase, NHS continuing care can be awarded to anyone whose needs are deemed eligible.

The other issue that occurs with NHS continuing care is the difficulty experienced in understanding and navigating the process. Even health professionals said that they found the process to be extremely complex and many of the individuals who contacted the Inquiry described how complicated and confusing they found the process throughout their entire experience of NHS continuing care. The lack of information makes it very difficult for people to make progress towards claiming NHS continuing care.

"We have no support and no help and this backwards and forwards has been going on for eight months. Each agency says it is the others' responsibility but no one tells us anything. We do not understand and have been given no information on what CHC is or how it works."³⁶

Of particular concern was that it seemed many people were not always told about specific elements of the process. A number of submissions referenced that they were unaware of the appeals process – something that they should have been told about at the start of their application. Others who were supervising an application for NHS continuing care on behalf of a relative relayed instances where assessments were carried out on the individual without informing them or even telling the individual. Families are not given the right information about the NHS continuing care process. One anonymous submission detailed an application for her husband, which began in October 2011:

"Not until July 2012, when an appointment was made with the consultant geriatrician, was I given anything in writing about the process, its stages, how it should be implemented and our rights within it."

It is clear that NHS continuing care is not very well understood by the general public. The Department of Health has considered doing more work to raise general awareness of NHS continuing care, which would be very welcome. It is of concern, however, that individuals and families going through the NHS continuing care process are not always in full possession of the facts and options available to them.

When the Care Bill was being debated in the Lords before the 2013 summer recess, amendments were tabled to do more to promote the existence of NHS continuing care. The draft Bill has introduced a duty to provide information about the care and support available to individuals.

The Care and Support Alliance³⁷ called for NHS continuing care to be specifically included in the information and advice service that local authorities give, in order to ensure awareness of and signposting to NHS continuing care. They also called for a discussion about NHS continuing care to be included in all post-discharge plans so that those who may need ongoing support after leaving hospital are aware of the funding. These amendments were supported by Parkinson's UK and the Alzheimer's Society as members of the Alliance and who have participated in this Inquiry.

It is also clear that health and social care professionals are not always fully informed about NHS continuing care. It is vital that professionals who deal with those eligible for NHS continuing care receive full training, so that they can refer people appropriately for funding and provide them with accurate information.

Lack of advocacy and involvement

Many submissions, both from individuals and from organisations, described situations where families felt they had been excluded from the assessment process – despite the fact that the assessment is supposed to be ‘person-centred’ and involve families and carers.

This made it difficult for carers to get the information they wanted to support their relatives and ensure that they were getting the care they were entitled to. It was noted that there is often little support for the families, such as an advocacy service. Although Julie Hill did have an advocate for part of her case with NHS continuing care, she felt that a more widespread service would be of use because:

“very few people actually see an advocate. She did help me quite a lot. At the very end, even the advocate was intimidated by the PCT and she did not actually come to that final assessment because of intimidation, which I thought was appalling.”³⁸

Her husband George Hill, who has Parkinson’s, felt this was much needed.

“I think there is a desperate need for an advocate within organisations like Parkinson’s UK ... There are so many people who are not ready to go into a fight like that (which is what it is) and inevitably lose because they have got no one to fight their corner for them. My worry is that the funding is being spent by families that need not necessarily be spent.”³⁹

There were also situations where individuals, carers and families felt that they were excluded from the process, particularly when it came to the assessments for NHS continuing care. A number of submissions recounted assessments being done on their relatives without them being informed, or even with their relative’s consent, contrary to the National Framework. Below is a typical example:

“The CHC assessors visited mum in the nursing home, but failed to notify me of their visit, which goes against their own rules. The reason for their visit was not explained to mum and the nursing home didn’t seem to be aware of its significance either.”⁴⁰

If people are excluded from the process, not only does it contravene the specific guidance on the issue, but it also makes it much harder for families and carers to engage fully in the process, share their knowledge of the person’s health needs and ensure that their relative is getting the care they are entitled to.

Lack of condition-specific knowledge and consultation from appropriate health and social care professionals

The nature of Parkinson’s as an unpredictable and fluctuating condition, combined with its relatively low prevalence, means there is often a lack of understanding of the many difficulties experienced by people affected by the condition. This has presented as an issue for NHS continuing care, not just for people with Parkinson’s, but for other poorly understood conditions as well.

Many of the submissions referenced a lack of understanding about their specific condition, when individuals were assessed for NHS

continuing care. When people's condition or conditions are particularly complex, rare or unpredictable, this appeared to exacerbate the difficulties in ensuring that professionals took full account of the condition. This was particularly cited as an issue by the Spinal Injuries Association and the Alzheimer's Society. Both organisations referenced examples of where assessments were undertaken through a multidisciplinary team that did not include an expert in the person's specific diagnosis which tended to result in an inaccurate account of their need.

This submissions received from people affected by Parkinson's highlighted the fluctuating nature of the condition was often not taken into account by the assessors. Several people told us of examples where they highlighted the unpredictable nature of the individual's needs, suggesting that this should increase their scoring in certain domains of the decision support tool (and thus the likelihood of receiving continuing care funding), only to be told by the assessors that the individual's needs were seen as 'predictably unpredictable' and therefore warranted a lower score. Examples were provided with dementia and other conditions such as motor neurone disease where assessments had found that if someone had little cognition, it was felt that this meant that they had no emotional or psychological needs. The Alzheimer's Society said this contradicted current research around cognition, as it is believed that people with low levels of cognition still experience emotions and psychological needs and that these needs still require support.⁴¹

Of particular concern to a number of organisations was the lack of involvement of expert or relevant health or social care professionals in assessments. People affected by Parkinson's described how they had secured the support of their Parkinson's nurse to provide evidence supporting applications for NHS continuing care. However, the Parkinson's nurse was not involved in the specific assessment, nor was their advice sought, despite being noted as someone involved in the individual's care and treatment.

The Spinal Injuries Association (SIA) felt this was a particular issue, as the nature of spinal injuries mean it is possible to predict the prognosis and needed treatment with relative accuracy. As the condition does not fluctuate, it is possible to know what level of care an individual will need for the rest of their life. This can be done by a spinal cord injury NHS health professional. However, the SIA were aware that these professionals were often not involved in the assessments, nor were they consulted for their opinion on the individual. The SIA felt that this was resulting in inaccurate assessments that did not capture the individual's needs, which meant they were not getting the care that would support them.

This lack of detailed knowledge and understanding of people's conditions severely affected the quality of the assessments and the verdicts reached. It is of real concern that professionals with an expertise in the condition are not actually involved in assessments and that evidence provided by the professionals treating the person under assessment are not fully taken into account. It is vital that any assessment for NHS continuing care should involve the input of a health or social care professional, either as part of the assessment or via submitting evidence to the assessment panel. Ideally, this should be the professional treating the individual under assessment or, at the very least, one with expertise in the condition the individual has. This would lead to a more accurate representation of the individual's needs and consequently a more accurate decision on their eligibility for continuing care.

Cost shunting

The issue of costs being 'shunted' between health and social care was regularly highlighted in the submissions to this inquiry. As healthcare is free at the point of need and social care is currently paid by the user on a means-tested basis, there are significant implications for who is considered responsible for providing an individual's care.

As individuals in receipt of, or who may be eligible for NHS continuing care will have high levels of need, their care is likely to be extensive and therefore, expensive to whoever is paying for it. The current financial climate has had an impact on budgets, particularly on local authorities. A report by the Public Accounts Committee, published in May 2013, expressed concerns over these issues, particularly in relation to social services. The report commented that “Local authorities’ funding continues to be cut, yet the number of statutory duties they have has stayed the same, and in some areas, such as adult social care, the demand for services is increasing”.⁴² This pressure has had an effect on many areas of social services, motivating them to find ways to cut costs as much as possible.

While a number of the individual responses had initially been successful in obtaining NHS continuing care, their funding was subsequently withdrawn, at times without clear explanation or a suggestion that the individual’s needs had lessened. Many of the individual submissions felt that the decision to withdraw the funding was made for financial reasons, rather than a genuine change in needs. It is unfortunate that there is a lack of condition-specific data on NHS continuing care recipients, as it could potentially demonstrate the situation where those with progressive conditions are losing their funding.

Many of the submissions from organisations also felt that decisions about awarding funding were often predicated by budgets. Submissions and oral evidence talked about decisions being financially motivated, rather than based on an individual’s needs. It was noted in the evidence received that the number of people receiving NHS continuing care is decreasing. This seems counterintuitive, given the UK’s ageing population and increasing complex health needs. Evidence was provided of where certain PCTs had reduced their number of patients receiving NHS continuing care to a quarter of that level in approximately two years.⁴³ In Scotland, the number of people in receipt of NHS continuing care has fallen by 37 per cent in four years.⁴⁴

When people are deemed ineligible for NHS continuing care, responsibility for their care is transferred to local authorities. This care is then considered part of the social care system. This is means-tested and the individual is expected to contribute a certain level of funding until their assets fall below a certain amount. This can result in people who thought they were eligible for NHS continuing care being asked to pay large sums towards their care.

Some estimated that they have spent thousands supporting their relative while trying to arrange for NHS continuing care. As all assets are taken into account, (including property where the person has moved into residential care), others told the Inquiry they were informed that they would need to sell their relative’s house to continue paying for their care.

Cost shunting occurs when there is a conflict between health and social care as to who should be paying for an individual’s care. This has long been an issue across many different domains of care, but appears to be particularly prevalent in NHS continuing care. There is a lack of clarity between what is considered a health need and what considered is a social care need. It is this ambiguity that allows the two bodies to dispute responsibility for care and continually attempt to pass people between each other. In particular, this tends to result in individuals deemed ineligible for NHS continuing care becoming the responsibility of social services. If the cost then falls to social services, they may dispute responsibility and call for the individual to be reassessed for NHS continuing care – particularly if the individual is considered exempt from contributing much to their care. These delays can be extremely frustrating, as one submission detailed:

“The question of how organisations interrelate has been an issue throughout this whole process – and it is very difficult for patients, or their relatives,

to know what they are entitled to and who is responsible for providing it. When I initially said I would like support from social services (16 Aug 2010), the social worker informed me that the hospital would send them a formal notification. However, their (16 Sept 2010) social worker told me it would be more appropriate if I co-ordinated the care myself, as my mother would be self-funding, and she also informed the OT [occupational therapist] of my mother's financial situation.

“ I learnt, after my mother was discharged, that social services have a joint responsibility with the NHS for safe discharge and should have carried out a community care assessment. If they had done, it might have identified that the provision of physiotherapy was appropriate, as well as perhaps helping to establish a more accurate picture as to whether my mother's needs were actually greater than social services are allowed to provide.”⁴⁵

.....

This shunting of responsibilities can be extremely distressing and difficult for people trying to claim NHS continuing care. It can result in people being asked to pay sums that they did not realise they were responsible for paying. In a number of cases the appeals process then reveals that they should not have been paying for the care anyway. Continuing to change which organisation is responsible for providing care can result in a change of care setting and care professionals, which may cause difficulties in ensuring continuous standards of care.

This is a significant issue with complex conditions such as motor neurone disease, or conditions where there are communication difficulties. This is because carers are required to take some time in order to develop a close relationship with the individual to ensure that their needs are being fully met.

With the current economic situation, it is unsurprising that organisations are unwilling to take on unnecessary costs. It also cannot be denied that individuals in receipt of NHS continuing care can represent a high level of cost. With the changes to the NHS designating CCGs as the organisations responsible for making decisions around eligibility for NHS continuing care, it is possible that cost shunting may be further exacerbated. They will cover smaller areas, making large costs such as funding NHS continuing care recipients more prominent in their budgets.

The lack of clarity between what is a health need and what is a social need has been raised many times as one of the contributing factors to the difficulties experienced with NHS continuing care. It is yet to be addressed, although it is extremely difficult to find a precise definition. The Commons Health Select Committee inquiry found that “representatives from SHAs and PCTs and local authorities, all senior officials working at the interface of health and social care on a daily basis, were ... unable to supply a definition.”⁴⁶

Despite the government's assertion (in its response to the pre-legislative scrutiny of the Care Bill) that the boundary between health and social care is already clearly defined,⁴⁷ this is not occurring in practice and the continued confusion is to the detriment of people using both health and social care. From the evidence received by the Inquiry and other work by Parkinson's UK, this boundary is not understood and is not consistently used. If there is a clearly defined boundary, it should be widely promoted so that individuals, professionals and organisations are fully aware of it. This will help ensure there is no disagreement about whether an individual's needs are the responsibility of health or social care.

Clear practical illustrations of what is a primary health need should be developed, through consultation with health and social care professionals and service users, to reduce the current ambiguities that continue to plague both systems. The Coughlan judgement provides a clear example of a case that defines the quality and quantity of need – and there must be many more cases which could be used to illustrate that need, particularly from those who are now in pilot areas in receipt of personal health budgets. These are illuminating to the public and to professionals what a primary health need is.

A fundamental issue is the NHS's interpretation of what services it now provides. Key commentators including the King's Fund have observed that there has been a gradual redrawing of the boundaries by health, with the NHS concentrating on acute and primary care and effectively 'withdrawing' from its responsibilities for community based services.

The fact that commentators, including the health select committee have observed that Pamela Coughlan would not qualify for NHS continuing care under the current assessment process is a further example of this. The King's Fund described this as "a trade-off that has been arrived at almost entirely by stealth in an unplanned way without explicit debate, decision or scrutiny."⁴⁸

The Decision Support Tool

The Decision Support Tool (DST) was frequently identified in submissions as one of the main barriers to individuals successfully receive in NHS continuing care, despite it being introduced as a way to help assessors to capture a more comprehensive insight into a person's needs.

Steve Ford, Parkinson's UK's Chief Executive described the DST as "a tick-box exercise rather than forming a collective picture of someone's

needs."⁴⁹ One issue that was commonly noted was that the DST was often being used inappropriately. Rather than being viewed as a tool to aid decision-making, it is being used overly prescriptively. Karen Guy, a Parkinson's nurse specialist, made the following comments in her written submission:

"It is not used as a support tool but being interpreted legalistically. The focus of the assessor is on the semantics of each word rather than the essence of the patient's condition. It is often used literally and not interpreted intelligently."

Aside from the flaws identified with the way the DST is used, a number of submissions identified specific areas where the tool did not provide an accurate portrait of a condition and subsequent needs. Sue Ryder's written submission detailed some particular issues with the tool.

"The DST is not appropriate for assessing progressive/fluctuating long term neurological conditions. The tool does not record the nuances between domains nor allow for, or take into account, good and bad day assessments."

Submissions discussed where domains within the DST were inappropriate for certain conditions. For example the Motor Neurone Disease Association deemed it inappropriate to consider non-complicit behaviour in someone who was paralysed. The submissions also highlighted that domains were missing from the current list. For example Karen Guy felt that lack of sleep was a domain that should be recorded due to the impact on quality of life. The submissions also detailed where a use of the DST resulted in contradictory findings. Parkinson's UK had been given an example of where someone with Parkinson's in receipt of NHS continuing care had undergone a reassessment.

Since the previous assessment, the individual's mobility had deteriorated to the extent that they were now permanently bed bound. The use of the DST then gave the individual a lower score in the mobility category because they were at a reduced risk of falling. This subsequently rendered the individual ineligible for NHS continuing care. While it is logical to assume that someone who is bedbound is less likely to fall over, it is completely illogical to then deduce that this means their overall health needs have lessened.

A related issue that arose through the submissions was that of 'well-managed needs' and how they were assessed. Similarly to the above example with Parkinson's, a number of organisations gave examples of where an individual's condition had been stabilised, only then to be viewed as a reduction in their needs. Several examples were cited where assessments concluded an individual had improved, despite this being very unlikely, given the condition.

"Despite the fact that spinal cord injury is a non-improving condition for which there is no medical cure, there are many examples of care packages being dramatically reduced after reassessments without there being any evidence of beneficial clinical improvement."⁵⁰

This was also a common issue that occurred with people affected by Parkinson's. Individuals with Parkinson's would go for reassessment for NHS continuing care, only to be told that their condition had improved and they were no longer eligible. Given the progressive nature of the condition, such a conclusion is illogical and for the individual who has then lost their funding, extremely distressing and potentially very expensive in order to maintain the same level of care – care that they still need.

Although there have been many criticisms of the use of the DST, the Department of Health has made it clear as to how it should be used. The guidance quite clearly states:

"The DST should be completed by a multidisciplinary team, following a comprehensive multidisciplinary assessment of an individual's health and social care needs and their desired outcomes. The DST is not an assessment in itself."⁵¹

The tool was introduced in order to help a multidisciplinary team to reach a decision about eligibility for NHS continuing care. The Spinal Injuries Association suggested during their oral evidence session a theory explaining why the tool was deliberately described as a support tool as opposed to a decision-making tool. This was that if it was a decision-making tool, it could be challenged in the courts. It is extremely important to note that some commentators have observed that Pamela Coughlan would not be considered eligible for NHS continuing care if the DST had been used to assess her needs.

Despite the Department of Health providing a clear explanation about the purpose and use of the DST, it is still being used inappropriately. This means the assessments of certain individuals for NHS continuing care are not being conducted fairly and the full extent of certain conditions are not properly taken into account.

Other issues with the assessment process

The assessment process for NHS continuing care was noted as being problematic by many of the submissions received by the Inquiry. As well as the issues detailed with the DST, the evidence received highlighted some other key areas that were causing difficulties for those attempting to claim NHS continuing care.

A common theme was the lack of focus on the individual's needs when undergoing the assessment process. Many people had unpleasant experiences throughout the assessment processes. This often started with the individuals and their families being asked about their current financial situation and how much they had in the way of assets. As the Royal College of Nursing noted:

“This is the wrong way round and the NHS should always carry out its assessment first, to ensure a patient's health needs are appropriately cared for.”⁵²

Many of the individual submissions who had this experience raised concerns that the first priority when discussing care was who was going to pay for it, rather than what the individual actually needed and felt this demonstrated a lack of empathy with their situations.

Unfortunately, a lack of empathy when it came to the assessment process for NHS continuing care was commonly reported by both individuals and organisations. Sue Ryder had received anecdotal evidence from both their neurological and palliative care services about the lack of empathy throughout the whole process.

“Assessments can last up to three hours and be extremely distressing. It is very tough for distraught relatives to have to describe the intricacies of their loved one's condition.”⁵³

The process was also deemed by health and social care professionals as extremely complex, protracted and bureaucratic. In their written submission, Sue Ryder estimated it took a full day to complete all of the forms in order to apply for NHS continuing care, including consulting with all of the relevant professionals involved in the individual's care.

Many individuals felt that there was a lack of transparency within the process and that it was difficult to ascertain why cases were being turned down, particularly when professionals had initially considered them eligible. David Goff provided a particular concerning example:

“We went through these processes with the MDT [multidisciplinary team] panel, getting rejected each time. The third time we discovered one of the people who was on the MDT panel, who had said collectively yes, we think he is absolutely eligible, was on the ratification panel that then rejected him. So it just seemed extraordinary. Although we could never say for sure, it just seemed that there were some tactics being used and they were using the process maybe for financial reasons to try to reject us for continuing care.”⁵⁴

Many of those who had undergone an assessment felt that the assessors were often looking for reasons not to find the individual eligible for funding. Although the Parliamentary and Health Service Ombudsman highlighted that “the final decision is a clinically-led one, and not based primarily on the observations of relatives and their own interactions with the person concerned,”⁵⁵ there were many examples of where assessments took an overly optimistic view of an individual's needs, resulting in an inaccurate assessment.

“Mum was questioned by the CHC Assessor, and being the sort of person she was, and being unaware of the purpose of the visit, she just said everything was 'fine' because she never liked to put anyone to any trouble and she rarely mentioned her pain, or the distress the Parkinson's symptoms caused her.”⁵⁶

Appealing against decisions

Another issue highlighted with the assessment process is when individuals reach the end of the process and wish to appeal. At present, there is no completely independent arbiter to deal with NHS continuing care complaints and redress early on, making the NHS both ‘judge and jury’ of assessments of NHS continuing care.

If an individual is dissatisfied with the decision made, they can go through the complaints procedure locally, including an ‘Independent Review Panel’ with an independent chair. However, NHS England is responsible for organising this system.⁵⁷ Once this has been exhausted, the next step is to go to the Parliamentary and Health Service Ombudsman, which is independent.

This will be at the end of an already very long process, as some respondents detailed having spent months and even years following up their complaints. There are also limits to what the Ombudsman can do in terms of bringing about changes to local areas. The Alzheimer’s Society expressed concerns about the efficacy of the current complaints process.

“It is not clear whether there is any follow-up when independent reviews and ombudsman investigations identify examples of where a CCG has not followed its legal duties with regard to following the framework.”⁵⁸

A number of submissions expressed concerns that even when problems were identified through external reviews and investigations, it was difficult to ensure that any recommendations were fully implemented. The establishment of a truly independent arbiter, such as the independent care tribunal recommended by the Joint Committee on the Draft Care and Support Bill, would give individuals an opportunity to have their appeals

heard in detail and potentially receive appropriate redress for any unfairly incurred costs.

During the appeals process the independent review panels rarely see the individual, which seems counter-intuitive. A family member has to go and represent themselves, which can be at a venue far away. The delays to the process of reaching appeal have also meant that some individuals attempting to claim NHS continuing care died before a decision was finally reached about their eligibility. This is extremely distressing for their families.

It is clear from the evidence received that there are a number of significant difficulties encountered with both the assessment and appeals process for NHS continuing care. With many issues identified with the process as a whole, it is unsurprising that the assessment was criticised in the vast majority of the submissions, both from individuals and organisations. The assessment is extremely complex, but if there are appropriately trained professionals undertaking it then it should not necessarily present any difficulties, as the British Association of Social Workers commented:

“The most important thing in any assessment is that the person completing the assessment understands it and the detail of the person’s needs are well described.”⁵⁹

It is worth noting that there will always be complaints made over decisions about NHS continuing care. However, the current process for pursuing appeals is such that it can result in individuals spending months or years waiting for their appeals to be upheld and at times even longer for a resolution to be reached – ie being compensated for unfair care costs incurred. It is also worth noting that individuals are often pursuing expensive legal action to challenge poor decisions made by their local NHS. A new, more responsive system is needed to help individuals achieve redress without having to resort to this.

The Joint Committee on the Draft Care and Support Bill recognised the potential for an increase in appeals with the proposed changes to the social care system and hence proposed the introduction of an independent tribunal to adjudicate on dispute over care costs. This would ensure that there is an independent arbiter to decide on eligibility for support with funding. NHS continuing care has resulted in many individuals disputing care costs, so this would provide additional support and help them to find a quicker resolution to their cases.

Delays

A common theme raised about NHS continuing care in many of the submissions was the delays that frequently occurred throughout the process. This was detailed in both standard applications for NHS continuing care and through the ‘fast-track’ option for individuals entering an end-of-life stage. Sue Ryder had particular concerns about the impacts of these delays:

“All of our hospices experience a delay in application outcomes, with many taking six to eight weeks to come through. We have even heard of it taking up to four months for the CHC team to follow up on an initial referral and make an assessment.”⁶⁰

The current National Framework for NHS continuing care states that a CCG should make a decision within 28 calendar days. This is from when the checklist is received by the CCG and when the final decision on funding is reached. The framework provides details on how to react if the decision takes longer, but stresses these should be unavoidable reasons. The framework does make it clear that:

“However, wherever practicable, the process should be completed in a shorter time than this.”⁶¹

It is worth noting that the framework only stipulates the 28 days as a guideline for the decision being made after receiving the checklist. The framework calls for each CCG to set out timescales for reviews of decisions, but does not give guidance on how long they should be.

A number of the submissions detailed significant delays in the NHS continuing care process. This occurred particularly in terms of actually getting the assessment carried out. Below is a typical example:

“I asked for a checklist to be done and this happened Nov-Dec 2011. They said a full assessment would be done and a MDT meeting would take place. This happened 17 months later in April 2013.”⁶²

Another respondent described making an application in August 2012 and, having been unsuccessful, trying to appeal against the decision. By May 2013, the family had not yet been told when their appeal would be considered due to the backlog of 300 applications. There rarely appears to have been any clear explanation provided for why the delays were so extreme, contrary to Department of Health guidance.

This is of particular concern with progressive conditions, including Parkinson’s, if there is a significant delay between identifying an individual who may be eligible and then actually carrying out an assessment. Sue Ryder expressed particular concerns over the impact of delays for individuals with motor neurone disease

“For one of my patients it took four months from the forms being sent out until the CHC team went to assess them. This is totally unacceptable. For MND patients particularly this is too long, as an individual’s condition can deteriorate very rapidly.”⁶³

In addition, there has been a significant backlog of backdated NHS continuing care cases awaiting review. A deadline was set for September 2012 for any claims made between 2004 and 2011. In May 2013, an article in the Health Service Journal estimated that there are 60,000 cases awaiting review, which would take at least five years to resolve, at substantial costs to the new CCGs who had inherited these liabilities.⁶⁴ When interest is also accrued for outstanding claims, estimates suggest that this could reach £600m.⁶⁵ The article noted that CCGs have now inherited these claims are looking at taking out loans to cover the costs of backdated NHS continuing care claims.

As identified above, the process for applying for NHS continuing care is extremely complex and takes a long time. It is clear, however, that this is exacerbated by delays within the process, resulting in individuals waiting for assessments. This can mean delays in hospital discharge or people having to pay for the costs of care in the meantime. Many of the submissions received made reference to being told of delays and backlogs within the system. The delays appeared to get worse when individuals attempted to appeal against decisions. Even though timescales for some stages are given in guidance and were recently introduced for dispute resolution stages,⁶⁶ it is clear guidance is not enough and does not enable people to go through each stage of the process in a timely way. People are still waiting unreasonably long times in order to navigate their way through the process.

Lack of a consistent approach at local level

One of the key issues identified in virtually all submissions from national organisations was the inconsistency that exists within the assessment and implementation of NHS continuing care in England.

The Parliamentary and Health Service Ombudsman clearly identified this as “the key problem we see” with the complaints they receive about NHS continuing care, of which they see about 500 per year with approximately 200 that are investigated further.⁶⁷ This has resulted in the number of people being awarded NHS continuing care varying greatly across England. In their written submission, the Local Government Association noted that levels of people who had been found eligible for NHS continuing care varied from 3.3 people per 10,000 population to 31.7 people per 10,000 population. They felt this meant that identification of eligible people was being conducted inconsistently.

Responses received from national organisations gave examples of inconsistencies in implementing the National Framework for NHS continuing care and the Decision Support Tool, right through to the appeals process. Sue Ryder identified this with their palliative care services that covered different authorities. This even occurred in care centres that covered two counties. In their oral evidence session, they detailed very different experiences of how two PCTs referring to the same hospice operated. One was a very positive experience, with staff taking a proactive approach. The other was less so and it was admitted that they found working with that PCT much more difficult.

It was also noted that inconsistency with NHS continuing care was not restricted to its implementation – the English Community Care Association commented that “there is no common methodology used throughout the country to determine fair fees”⁶⁸ for NHS continuing care. That, coupled with a lack of understanding about costs of care within care homes, made it difficult for costs to be accurately calculated.

It is worth noting that some submissions provided evidence of high quality services that supported individuals. The MS Society provided a very encouraging example in their written submission to the inquiry:

“In the North East the LA [local authority] and the PCT [Primary Care Trust] have undertaken joint assessments and the transition from total LA funding to joint CHC [NHS continuing care] and LA funding has been smooth. One of our members reported that they had recently had a joint assessment for CHC with their LA, as the LA believed their needs had gone beyond what the LA could provide for. The meeting was set up by the local authority and the assessment was jointly done by both agencies. The person felt involved and in control and all options were fully explained to her.”

It is important to recognise that NHS continuing care is not universally poor – the evidence submitted to the inquiry demonstrated pockets of good practice that appropriately support eligible individuals. However, the fact remains that there is no consistent approach to the implementation of NHS continuing care throughout the entire process at a local level, affecting the quality of care received by individuals. There is also no consequence to CCGs not complying with the Department of Health requirements for NHS continuing care. In fact, the only real consequence for CCGs is that they are less likely to have to pay for an individual’s NHS continuing care.

With such little national oversight and without any clear incentive for CCGs to support and assess people for NHS continuing care properly, people may fall through the cracks. With the current emphasis on cost cutting in the NHS, CCGs may be even more keen to shunt costs for provision of an expensive care package like NHS continuing care onto social services or onto individuals themselves. Therefore, quality assurance and auditing must be undertaken by NHS England and the Department of Health to ensure CCGs raise their standards and ensure a consistent implementation of NHS continuing care across England.

Lack of data or monitoring

One point that became very pertinent to this Inquiry was the almost total lack of useful data and monitoring of NHS continuing care. At present, the main data available from the Department of Health only details how many individuals are claiming NHS continuing care in England, broken down by PCT area⁶⁹ recorded every quarter. The only other data recorded is the amount spent on NHS continuing care cases in England as an aggregate figure. There is no stringent monitoring framework in place to ensure that the NHS is fulfilling its obligations to individuals applying for and in receipt of NHS continuing care.

As a result of this approach, there are some readily apparent gaps to the government’s understanding of the real situation with NHS continuing care. When asked about the number of outstanding cases in a parliamentary question, the government’s response was as follows:

“The Department does not collect information on the numbers of NHS Continuing Healthcare cases awaiting assessment.”⁷⁰

From looking at similar parliamentary questions, it is apparent that the Department of Health does also not collect information on the primary diagnosis of people in receipt of NHS continuing care⁷¹ nor the number of requests for reassessments or refunds.⁷² There is also no concrete information available on how long individuals are in receipt of NHS continuing care, how long it takes them to go through the assessment process or how many individuals apply unsuccessfully. There is no other data that might highlight equality issues such as age or ethnicity of recipients. Although there are may be other things to monitor, the listed information above is the bare minimum needed in order to gain a picture of how NHS

continuing care is functioning in England, who is being supported by the system and who is not getting that support.

The current data collected can be analysed to identify the stark regional variations, but without any additional supporting data it is difficult to scrutinise the reasons for these. Data is needed in order to understand the process of assessment and appeals in more detail.

The Spinal Injuries Association expressed concerns about the lack of centralised data collection and monitoring, and the potential negative impact the NHS restructure has:

“ There is not even a vested interest in an overview of how continuing health care is applied across the country. In reality, the Department of Health (and under the new NHS structure I think it is happening even more) is becoming one step removed from the actual implementation on the ground, and with the separation in terms of legal entities of the CCGs from NHS England ... nobody is able to look at what a health authority is doing and say they are doing this wrong because they are entities in and of themselves. There is nobody overseeing the whole system. There is nobody looking at the national picture and asking questions as to why the different areas are showing such variation in continuing health care awards. Even when they are looking they cannot mandate anything because the health authorities are autonomous and so the assessment processes are largely autonomous as well.”⁷³

While it may not be possible to answer the question as to why the Department of Health has chosen not to closely monitor the implementation of NHS continuing care in England, it cannot be denied that the amount of information and data collected about NHS continuing care is inadequate, resulting in no clear national picture of how NHS continuing care is operating in England. Interestingly, the evidence submitted to the Inquiry by the Department of Health did not raise any specific concerns about how NHS continuing care is currently working. From the other evidence received by the Inquiry, it would appear that there are some fundamental areas of concern with NHS continuing care. NHS England now has responsibility for NHS continuing care at a national level, and they should look to establish a much more comprehensive dataset.

It is clear that the number of significant omissions in the data has resulted in a lack of accountability for NHS continuing care within national government and local health bodies. It is probable that this lack of oversight has led to a situation where NHS continuing care presents individuals with severe challenges. It can only be through national oversight and monitoring of the implementation of NHS continuing care that consistency will be achieved.

Lack of consequences for non-compliance

One of the key issues identified by many of the submissions who had a negative experience was the general lack of adherence to Department of Health guidance on NHS continuing care. There are a number of issues that have already been discussed in this report that illustrate a number of ways in which NHS continuing care is not being consistently or correctly implemented, to the detriment of individuals and their families trying to navigate the system. However, it is

clear that, at present, there are no significant repercussions on the organisations involved in NHS continuing care who do not comply with the National Framework for Continuing Care.

From the evidence received, there were a number of instances where procedure was not correctly followed. These varied from families not being told about the appeals process, to over-reliance on the DST during the assessment, to long and unexplained delays to the process. However, there is no penalty on the assessors or the CCG for these. The longer that a case for NHS continuing care is not paid, the longer that a CCG does not have to pay for that care. If someone is subsequently found eligible, the costs of their care can be backdated and the CCG must then repay either the local authority or the individual depending on who was funding the care, although it is by no means certain that people are compensated fully for all the costs incurred to them.

If anything, there is almost an incentive to avoid resolving cases or finding individuals eligible for NHS continuing care, and individuals report being so worn down by the process they give up. A number of respondents commented that their local health authorities appeared to seek any justification for not awarding funding and it was thought by some that this may be due to financial reasons.

Again these reports show how the Department of Health/NHS England should provide national oversight and use data, quality assurance and auditing mechanisms, and ensure those individuals who win their appeals for NHS continuing care receive full compensation for any unfair costs incurred.

Choice of services and professionals

For those that have successfully been granted NHS continuing care, there are still a number of difficulties in ensuring individuals receive the appropriate care. This can be attributed to a number of factors as detailed in the submissions.

It was suggested that there is a lack of flexibility when it came to applying NHS continuing care funding to an individual's care package. A number of submissions representing those who provided care services felt that being awarded NHS continuing care meant that the individual had to change their care arrangements, including taking on different care workers. A common request was that the individual needed to go into residential care, despite the fact that an NHS continuing care package can be provided in any setting.

When someone has complex needs, the ability to consistently retain the same staff providing services funded by NHS continuing care is extremely important. Mark Stone from the Motor Neurone Disease Association explained that the communication difficulties associated with the condition meant that it took time to develop a relationship with the individual.

“To understand that [their needs], you need to be very familiar with them, and so having consistency of carers and consistency of care workers is really important.”⁷⁴

When it came to finding these new care packages and staff, concerns were raised about how it took place. Sue Ryder's Dominic Carter outlined the difficulties in asking the NHS to arrange this type of care.

“There are quality issues around people who are not very well versed in the different care agencies choosing who is going to be delivering that care. It ends up almost like looking at the Yellow Pages and ringing round to see who can provide care.”⁷⁵

One solution to this proposed by several submissions was the use of personal health budgets. From April 2014, anyone who receives NHS continuing care has the right to ask for a personal budget for that care. However, the Minister for Care Norman Lamb has recently announced that this will now be bolstered by a ‘right to have’ a personal health budget from October 2014.⁷⁶ In particular, the MS Society had been involved in some of the pilot schemes and felt that it would increase choice and control for individuals in receipt of NHS continuing care. Other individuals felt that a personal health budget would allow for a more flexible care package to meet individuals’ needs.

“The standard practice once continuing care has been awarded seems to be two people going to a patient four times a day, or admission to a nursing home. This is too rigid. My husband needs stimulation, some exercise, some variety in his existence. A personal budget that could be flexibly applied not only to give morning and evening care but also maybe a skilled carer to take him out in the wheelchair or go through an exercise routine with him would be much more beneficial.”⁷⁷

From the submissions received, the lack of flexibility once people were granted the funding caused unnecessary disruption to their care as the new funding appears to necessitate changes to their care packages, such as different care workers.

Despite Department of Health guidance which states that NHS continuing care can be provided in any setting, individuals are still being pushed towards receiving this care in different care settings or with different professionals, against their own preferences. The introduction of personal health budgets may allow individuals to exercise greater choice and control over their NHS continuing care packages, which is very welcome. But it is vital that this choice is properly informed and that there is clarity on how the NHS will calculate the person’s proposed Personal Health Budget, so people can achieve the outcomes they wish. Individuals must be aware of their rights under NHS continuing care and they must be able to retain current care packages if appropriate.

Part 3: Conclusions and recommendations

Conclusions and recommendations

From the evidence submitted to the Inquiry, it is clear that the system for NHS continuing care in England is not fit for purpose and is failing vulnerable people and their families at a time in their lives when they need the most support. From individual cases, to the professionals, to the patient organisations, to the body that handles complaints about the system, virtually every respondent felt that NHS continuing care was not operating properly. The fact that individual submissions requested their details to be kept anonymous, for fear of recrimination, suggests that difficulties with NHS continuing care can create an atmosphere of fear and intimidation. A number of individuals who gave evidence to the Inquiry had clearly found the process an upsetting and distressing experience.

It is important to note that many of the issues identified in this report have previously been acknowledged by previous investigations and

reports. It is further important to note that, despite some changes to NHS continuing care by the governments of the day, the system has yet to see any extensive improvement.

The evidence received by the Inquiry shows there are a number of clear conclusions that can be drawn about what needs to be resolved with NHS continuing care and accompanying recommendations for action.

Recommendation: That NHS England must understand and meet the demand for these services by collecting condition specific data, at every stage of the process for those applying for NHS continuing care.

It has become clear that one of the reasons that individuals experience difficulties with the system for NHS continuing care is that the system is not being monitored sufficiently at a local and national level. The cursory amount of data recorded by the Department of Health means that it is difficult to form a national picture of how NHS continuing care is performing as a funding package. As a result, there is no way for the Department of Health to take action against specific health bodies that are failing to follow their guidance. At present, when issues with NHS continuing care are raised, it is only via recommendations through organisations such as the Parliamentary and Health Service Ombudsman, who cannot compel organisations to make any changes. We need to have better local and national data on NHS continuing care so that we are aware of who is claiming, how long they are claiming it for and which conditions they have.

Recommendation: That NHS England must end uncertainty for those involved in assessments by establishing an improved national framework with clear processes, guidance and timelines for decision making, applied by Clinical Commissioning Groups (CCGs) who are held to account by NHS England for their performance.

A number of submissions made reference to instances where the process for NHS continuing care was not correctly followed. Due to the lack of supervision by central government, there are no consequences for those who do not comply with the guidance. In fact, as often this lack of compliance seems to result in individuals not being awarded NHS continuing care, it benefits them financially. In order to see clear improvements to the system, it is vital that real ‘teeth’ be given to the National Framework for NHS continuing care and that there are negative consequences for bodies who do not comply with NHS continuing care guidance. There is now case law that stipulates when the NHS are responsible for providing care and when social services are responsible. This must be taken into account when making such decisions.

The lack of any substantive guidance on timelines for the NHS continuing care process means that many cases are kept waiting weeks and months for their cases to be resolved. If it is decided to take the case to appeal, this can involve waits of months and even years. During that time, it is likely individuals are paying for care unnecessarily and also engaging solicitors to support them through the process – this is completely unacceptable. If individuals do decide to appeal, the fact that the only method of recourse is via the Parliamentary and Health Service Ombudsman means that getting a final answer can be an extremely prolonged process.

It is clear that there is a real need for the NHS England to put in clearer indications about timescales for navigating the NHS continuing care scheme, so that CCGs have a clearer idea of how they should be performing. This could also be included in guides for authorising CCGs. Many individual submissions made reference to being told about a backlog as a reason for the delay. This could perhaps suggest that greater investment is needed in the assessment of NHS continuing care to ensure individuals in need are granted funding as quickly as possible.

Recommendation: That NHS England must 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.

Further support could also be provided with the decision making process. In many instances the Decision Support Tools is failing people – not only is it being overly-relied upon by health and social care professionals in the decision making process but certain ‘domains’ of the tool were also found not to be adequately reflecting people’s conditions – this was both for those with progressive and fluctuating conditions and for those with ‘well managed needs.’

Recommendation: That NHS England must 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.

Appealing a decision about NHS continuing care is time consuming, protracted and difficult. A number of submissions were able to resolve their cases by accepting less than the full amount to which they were entitled. Considering that this can be a difference of thousands to pay for the levels of care required and that health care should be free at the point of delivery, it is only right and fair that individuals who have incorrectly incurred such costs are fully compensated.

The Joint Committee on the Draft Care and Support Bill have suggested an independent tribunal to hear legal disputes over costs of social care and NHS continuing care. There needs to be a truly independent arbiter to hear appeals and rule on what individuals are entitled to.

Recommendation: That NHS England must 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.

There is also the issue of individuals losing their eligibility through inaccurate reassessments. This is often because they have a stable condition where their needs are unlikely to change or because they have a progressive condition, such as Parkinson’s where their needs will only get worse. As with benefit assessments such as the Work Capability Assessment, it seems illogical to believe that such individuals might improve and this should be factored in when reassessing their cases.

Recommendation: That NHS England must 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 NHS continuing care.

From the individuals who gave evidence to the Inquiry, the complexity of the NHS continuing care process was clearly extremely daunting. Many people talked about having to become overnight ‘experts’ in a complicated legal process, to support their or their relative’s application. Those that got involved in their relative’s application often felt that their relatives were in a fortunate position to have someone able to take this on for them and worried for those on their own without someone able to take the process on. It was suggested that the use of advocates might help people to navigate the process.

At present, there is ad hoc support for those applying for NHS continuing care. The Spinal Injuries Association has a dedicated advisor on NHS continuing care, the Alzheimer’s Society has an NHS continuing care Volunteer Support Group and Parkinson’s UK provides advice through

its helpline. All of these provide some levels of support for those experiencing difficulties with NHS continuing care. It is perhaps through peer support groups, such as the one run by the Alzheimer's Society, that charities may be able to provide additional support for individuals by putting them in touch with others who have undergone the same experience. As NHS continuing care is currently the third most common reason people contact the Parkinson's UK helpline, this could be a strong justification for the charity exploring how else they can provide support and advocacy on this issue.

Many changes have been taking place in England to health and social care, so it is vital that NHS continuing care is improved upon in light of those changes. While there are a number of flaws with the system, in theory it can and should provide support for seriously ill people at a time when they are very vulnerable. For some, this does occur. However, the evidence from this inquiry has seen that the system of applying for NHS continuing care is confusing, difficult to navigate and stressful, with many people being left to cover costs that they should not be paying. We hope that our report, and the recommendations within it, will lead to improved changes for those desperately in need of support.

Glossary of terms

All Party Parliamentary Group – informal cross-party groups of MPs and Lords that are set up around specific issues. The All Party Parliamentary Group on Parkinson's was set up in 2008 with the aim of raising awareness of Parkinson's in Parliament.

Clinical Commissioning Group – local organisations set up to commission local health services in England. They took over this role from Primary Care Trusts with the introduction of the Health and Social Care Act 2012. At the time of writing, there are 211 Clinical Commissioning Groups authorised to operate by NHS England.

Decision Support Tool – a document published by the Department of Health to support health and social care professionals to apply the National Framework for NHS Continuing Healthcare and NHS-Funded Nursing Care. The document aims to help professionals to make decisions about eligibility in a consistent manner.

Multidisciplinary team – a group of health and social care workers who are members of different disciplines, each providing specific services to the service user. In relation to services for people with Parkinson's, a full multidisciplinary team should include medical specialists, nurse specialists, physiotherapists, occupational therapists, speech and language therapists, dieticians, clinical psychology, palliative care professionals and social workers.

NHS continuing care – a package of care arranged and funded entirely by the NHS, where it has been assessed that an individual's primary need is a health need. This care package can then be provided in the individual's care setting of choice, usually at home or in a residential care facility. This can be referred to by a variety of terms, including NHS Continuing Healthcare and fully funded NHS care.

Parkinson's nurse – a nurse practitioner with a specialist knowledge and experience in caring for people with Parkinson's. Key responsibilities including making and receiving referrals to other health care professionals, managing caseloads, providing information, education and support to people in their own homes, in clinics and in hospitals, and prescribing and monitoring medicines and treatments to people with Parkinson's.

Parliamentary and Health Service Ombudsman – a free and independent service established to investigate complaints about the NHS in England, UK government departments and other public organisations. The Ombudsman makes the final decision on complaints about these services made by individuals. The organisation has now combined the work of the Parliamentary Ombudsman and the Health Ombudsman.

People affected by Parkinson’s – this is a term used by Parkinson’s UK to denote anyone who might have Parkinson’s, who cares for someone with Parkinson’s or who has a close relationship with someone with Parkinson’s.

Personal health budgets – an amount of money to cover an individual’s health and wellbeing needs, which is planned and agreed between the individual and the local NHS team. The aim is to give people greater choice and control, as they are responsible for managing and paying for their care. There are also personal budgets, which perform the same function for individuals managing and paying for their own social care.

Primary Care Trusts – administrative organisations responsible commissioning health services. They were created in 2002 and abolished in 2013 as part of the Health and Social Care Act. At the time of their abolition, there were 152 PCTs covering all of England.

Social care – services that provide help for people to perform daily living tasks to ensure they remain safe and independent. This can be anything from assistance with personal tasks such as washing and dressing, assistive equipment such as grab rails or respite for the individual’s carer through breaks or access to a day centre. This can be provided at home or in residential care. More recently, it has been referred to as care and support, particularly in the discussions around the Care Bill.

Strategic Health Authorities – regional organisations set up to implement the Department of Health’s directives and fiscal policy. They were created in 2002 and were abolished in 2013 as part of the Health and Social Care Act. At the time of their abolition, there were 10 SHAs covering all of England.

Acronyms

APPG	All Party Parliamentary Group
CCG	Clinical Commissioning Group (see glossary of terms)
CHC	NHS Continuing Healthcare – a synonym for NHS continuing care
DH	Department of Health
DST	Decision Support Tool
MND	Motor neurone disease
PCT	Primary Care Trust

Participants in oral and written evidence sessions

The Inquiry received a total of 53 submissions, including 41 from people affected by Parkinson’s. Written evidence was provided by the following organisations:

- Alzheimer’s Society
- British Association of Social Workers
- Department of Health
- English Community Care Association
- Local Government Association
- MS Society
- Motor Neurone Disease Association
- Parliamentary Health Service Ombudsman
- Royal College of Nursing
- Spinal Injuries Association
- Sue Ryder
- West Lancashire Clinical Commissioning Group

Oral evidence sessions

June 12 2013

- Steve Ford, Chief Executive, Parkinson's UK
- David Goff, person affected by Parkinson's
- Graham Price, person affected by Parkinson's
- Brian O'Shea, Continuing Healthcare Advisor, Spinal Injuries Association

June 19 2013

- George McNamara, Head of Policy and Public Affairs, Alzheimer's Society
- Mike Pearce, Head of the Alzheimer's Society's NHS continuing care Volunteer Support Group

June 26 2013

- Dominic Carter, Head of Care, St Johns Hospice, Sue Ryder
- Siobhain Aris, Advanced Nurse Practitioner, Leckhampton Court Hospice, Sue Ryder
- Karen Guy, Parkinson's Disease Nurse Specialist, Royal Berkshire Hospital
- George and Julie Hill, people affected by Parkinson's

July 3 2013

- Hilary Fairfield, Regional Care Development Advisor (West of England), Motor Neurone Disease Association
- Mark Stone, Trustee, Motor Neurone Disease Association
- Sally Hughes, Head of Service Change and Development, MS Society
- Natasha Fiveash, carer of someone with Multiple Sclerosis

Panel members:

Parkinson's UK is grateful to the following members of the APPG on Parkinson's who took part in the oral evidence sessions:

Lord Brooke of Sutton Mandeville

Russell Brown MP

Baroness Finlay of Llandaff

Baroness Gale (chair)

Lord Harrison

Baroness Masham

Madeleine Moon MP

Lord Walton of Detchant

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To find out more about the Failing to Care: NHS Continuing Care campaign Parkinson's UK is launching based on the recommendations contained in this report please visit parkinsons.org.uk/failingtocare