

Social care Green Paper – Shaping the Future of Care Together

Response from the Parkinson's Disease Society

The Parkinson's Disease Society (PDS) welcomes the opportunity to respond to this important consultation. We support the vision of a National Care Service that would deliver a system of care and support across England, "which is not subject to a post code lottery¹." Addressing the current inequalities in social care is a major concern for people with Parkinson's. Problems in accessing social care have been highlighted in the PDS members' survey² and the recent All Party Parliamentary Group (APPG) for Parkinson's disease Inquiry Report³.

The PDS were keen to engage its members and supporters in the Big Care debate and surveyed members, branches and supporters to gain their views of the proposals in the Green Paper. The PDS believed it to be important to ask its members about proposals to abolish Attendance Allowance and the option of a tax funded system, and included questions on these.

1. PDS recommendations

- Attendance Allowance and other disability benefits to be retained in any National Care Service as an effective, flexible and popular means of meeting an individual's disability related costs
- Increase in tax or National Insurance should not be ruled out as part of the long-term funding solution
- The Government to publish full details of the calculations that underpin the Green Paper
- The Government to publish a timetable for its review of carers' benefits and include support for carers as a principle that underpins the National Care Service
- The National Care Service must establish a system that incorporates both care for working age disabled people and care for older people
- Joint working between health and social care should include the use of joint budgets
- Advocacy and advice are essential to support people to navigate the care system
- People with a long-term neurological condition to have a named point of contact for advice and information and coordinating the individual's care plan

- It is essential that preventative and early interventions in the management of long-term conditions are included in any prevention strategy.

2. About Parkinson's

It is estimated that 120,000 people in the UK have Parkinson's. Parkinson's is a progressive, neurological disorder, with no known cure. The three main physical symptoms associated with Parkinson's are tremor, muscle rigidity and slowness of movement. However not everyone will experience all three. There is also a long list of commonly occurring non-motor symptoms, which may or may not occur at different point throughout the course of Parkinson's. These include sleep disturbances, difficulties with balance, incontinence, problems with altered posture, tiredness, speech difficulties, pain and mental health problems such as dementia, hallucination and depression.

The severity of symptoms can fluctuate, both from day to day and with rapid changes in functionality during the course of the day, including sudden 'freezing'. Appropriate health and social care provision is crucial to enabling those affected to manage their symptoms, maintain quality of life and maximise their independence

As the condition progresses and there is a greater impact on daily living activities, this can result in an increased dependency for support from care providers, either family members or private or statutory care services. Maintaining normal activities such as work, family responsibilities or hobbies becomes increasingly difficult and assistance may be required in all activities of daily living to allow the person to maintain mobility and independence as far as possible. Without this assistance and support, the person with Parkinson's may often become socially isolated and this will result in a further deterioration in their quality of life. For effective care of people with Parkinson's, it is essential that health and social services are delivered in a joined-up fashion with effective communication between professionals.

Treatment of Parkinson's is largely made up of medication to replace, enhance or facilitate the production of dopamine within the brain. However, all classes of Parkinson's drugs are associated with significant side effects which in themselves can require management. In addition to drug management there is significant benefit to be gained by therapy intervention such as physiotherapy, speech and language, occupational and psychological therapies.

Parkinson's affects people from all social and ethnic backgrounds and age groups. The average age of onset of Parkinson's is between 50-60 years of age, though one in seven will be diagnosed before the age of 50 and one in twenty will be diagnosed before the age of 40.

3. Views of Parkinson's Disease Society (PDS) supporters

Members and branches were sent two questionnaires, one on how care and support should be funded in the future, which received 605 responses, and one on what a National Care Service should look like, which received 271

responses. Our response to the Green Paper is primarily based on the opinions expressed in these surveys.

306 respondents indicated that they were people with Parkinson's, 163 were carers, with fifty other respondents, the majority of whom were former carers. There was virtually no difference between the responses received from people with Parkinson's, carers and other respondents and the figures quoted below are based on all responses received. The main findings of the survey are:

Proposals to abolish Attendance Allowance (AA)

- Sixty two per cent stated that Attendance Allowance should not be abolished under any circumstances.
- Five per cent would be happy for AA to be abolished and incorporated into the funding of a National Care Service
- Seven per cent would be happy reduction in Attendance Allowance if the majority of their care needs were met by a National Care Service
- Twenty six per cent would support the abolition of AA if **all** their care costs were met by a National Care Service

Extra costs of disability

Sixty three per cent of respondents identified specific extra living costs due to their disability, including:

- Transport costs – 153 people
- Heating costs – 176 people
- Help with gardening – 62 people
- Extra laundry or cleaning costs – 117 people

Six principles

There was strong support for all six principles underpinning the Green Paper:

- Ninety three per cent supported a national assessment process
- Ninety one per cent supported joined up services between NHS and social care
- Ninety three per cent supported information and advice for all
- Ninety seven per cent supported personalised care
- Seventy five per cent supported a focus on preventative services
- Ninety three per cent supported a fair system of funding

Making the Vision a reality

There was strong support for a National Care Service with joined up services, choice and quality.

- Eighty five per cent supported joined up working across local public services
- Seventy two per cent supported a wider range of services and greater choice
- Eighty six per cent supported greater quality services and innovation

Funding models

- Fifty seven per cent favoured funding out of tax or National Insurance
- Twenty two per cent favoured the Comprehensive model
- Thirteen per cent preferred an insurance model
- Nine per cent favoured the Partnership model.
- Seventy eight per cent believed that accommodation costs in residential care should be included in the National Care Service.

National or local decisions on how much money to be spent on care

- Eleven per cent believed that decisions should be made by local government,
- Nineteen per cent that decisions should be made by national government
- Seventy per cent that decisions should be made by an independent national body.

4. Funding care and support

The PDS recognises that additional funding is required to sustain care and support in the future in order to meet the needs of an ageing population. We do not have a preference for how this additional funding should be achieved; however, we believed that the government was wrong not to seek people's views on a tax-funded option.

The Green Paper makes no specific reference to charging for care services and further clarity is needed on this. The proposal for the Comprehensive model suggests that all services would be provided for free, but it is unclear would this cover all services or just those above an eligibility threshold. These concerns are addressed in more detail in the response from the Coalition on Charging, to which the PDS are signatories.

4.a. Tax and National Insurance

We believe that the Government was wrong to rule out tax and National Insurance as one of the options for funding care in the future. For this reason, we included this option in our survey, along with the Government's three suggestions. It was favoured by a clear majority of respondents (fifty seven per cent).

Tax and National Insurance are already a key component of the social care system. Tax funding already underpins all of the models in the Green Paper and the future shortfall in funding may require increased tax in addition to any other system of funding. If overall expenditure on social care is to be doubled over the next 30 years, then it seems reasonable to expect that at least some of this additional funding should come from Government funding.

Since the Green Paper was published, the Prime Minister has made an additional commitment to provide free personal home care for those with the highest level of need. This additional money will ultimately come from general taxation, in which context it is strange that the Green Paper has ruled out any increase in tax.

“The tax option is the best. The Government should be courageous and not be so afraid of raising taxes to pay for services to its electorate.” **Person with Parkinson’s**

“The option ruled out is the most obvious choice as the system already exists.” **Person with Parkinson’s**

4.b. Comprehensive model

The Comprehensive model was by far the most popular of the three options proposed by the Government, favoured by twenty two per cent and by half (fifty one per cent) of those who did not support the tax and National Insurance model.

The advantage of this model is that it is clear that all costs will be met by the state. A system with a universal right to support and clarity about how to access that support is easy to understand and could address the majority of inequalities in social care.

“I like the option of a payment after death – sensible and workable.” **Person with Parkinson’s**

Of those who were against this model, the main concern was the one-off cost, which many people would be unable to meet; further detail is clearly needed about who would be liable to pay this sum.

Further detail is also needed about what level of need would be covered by the comprehensive model and what eligibility criteria would be used. The Green Paper refers to ‘basic care and support costs’, which suggests that not all needs would be met even under the comprehensive model. Responses to our survey showed that twenty six per cent of people would be happy for Attendance Allowance to be incorporated into the care system if ‘all’ of their costs were met; which would not be the case if the system only covered ‘basic’ costs.

It is also unclear how carers would be incentivised to provide care under a model where all care is provided for free. It is essential that carers are not forced to provide care and that they are supported in the care they do provide.

4.c. Insurance model

The insurance model was favoured by just thirteen per cent of all respondents, or twenty nine per cent of respondents who rejected a tax-based system.

“If the insurance scheme was affordable and sensitive to people's income, I think this is the fairest.” **Care worker**

The Green Paper rejects a tax-funded system on the basis that this would place too much of a burden on working age people. However, if the eventual

aim of this reform is that everyone takes out a form of care insurance, this would have an even greater burden on working age people than tax.

“How would people who have already been diagnosed with a condition qualify for insurance? How would they be able to pay for the insurance if they aren't able to work”? **Wife of person with Parkinson's**

One of the main concerns respondents expressed about the insurance-based model is that people with pre-existing conditions would find it difficult to obtain insurance. One in four of the 13,000 respondents to our 2008 members' survey⁴ reported that they have had a problem obtaining or claiming insurance.

Of these, 130 people reported difficulties making a claim for medical insurance. A recent example of this is a caller to our Helpline who developed Parkinson's whilst paying into a private insurance scheme. Several years' later he was forced to give up work, only to be told that because he renewed his insurance annually his Parkinson's was treated as a pre-existing condition and he wasn't entitled to claim. He is currently appealing this decision, but this is typical of the type of loophole that people report when trying to claim insurance.

The Green Paper acknowledges that this option would be “less relevant” to people with pre-existing conditions, i.e. that they have difficulty obtaining insurance, but makes the mistaken assumption that these will be able to obtain free care because they are on a low income. The majority of people with Parkinson's are likely to develop their condition later in their working life and are often in well paid professions.

The PDS is therefore extremely keen to know what protection there would be to ensure that people with pre-existing conditions obtain insurance, and what protection there will be to prevent loopholes, which could leave people liable for the full cost of their care.

“We've looked into this and found only one company willing to offer insurance and the cost was so high that we couldn't consider it.” **Carer of Person with Parkinson's**

4.d. Partnership Model

This was the least popular model amongst our survey respondents, with just nine per cent supporting this option, or twenty per cent of those who rejected a tax-based model.

The principle of everyone receiving a contribution towards their costs was welcomed. However, people with a long-term condition such as Parkinson's face a life-time of care costs, including likely residential care costs in the later stages of their condition, and it was widely felt that a contribution of approximately a third of all costs would still leave disabled people facing a huge accumulated cost.

Given that the model does not include ‘hotel’ costs during residential care, the true proportion of all costs borne by care users is likely to be even higher than two thirds of all residential care costs. In this context, it is hard to foresee how this model would prevent people with Parkinson’s having to sell their home to pay for their care.

It is also unclear whether the partnership model will fund a proportion of all care-related costs or just those above a particular level of need.

The above issues are a particular concern in light of the proposed abolition of Attendance Allowance, which would mean that people lose disability benefits yet only receive help with a small proportion of their care costs.

It is also unclear how younger disabled people will fare under the partnership model. There is an underlying assumption (page 108) that people of working age will get their care for free due to low income and assets. However, this is not true of people with Parkinson’s who develop the condition later in their working life.

4.e. Deferred Payments

The majority of respondents were opposed to accommodation costs in residential care not being covered by the National Care Service. Several commented that it was confusing that the Comprehensive Model referred to all care costs being met by the National Care Service, whereas in reality people would still be faced by a high level of residential care costs.

The Green Paper states that an average stay in a nursing home can cost £25,000 for two years for care, and that “**accommodation can cost as much again.**” Any of these models would therefore still leave people facing £25,000 accommodation costs for an ‘average stay’.

One of the problems with the current system is that people assume that their care costs will be met by the NHS. We are concerned that a similar problem would arise if a National Care Service is introduced offering free care in return for a one-off payment of £17,000 – i.e. people will assume this payment will cover everything.

Other respondents expressed concern about what happens to widows of people still living in the family home after the person dies. The White Paper should include detail on the protection for close family still living in the family home.

In spite of these concerns, there was widespread recognition of the benefits of a deferred payment system in preference to the existing system.

“I prefer a deferred payment system, so that older people with disabilities or health problems do not have to worry about these costs.” **Former carer of person with Parkinson’s**

I thought the £17000 above paid for it all!! What does that pay for? **Person with Parkinson's**

If you really need to go into a care home the Care Service should pay for it. **Carer of person with Parkinson's**

5. Proposal to abolish Attendance Allowance

The PDS recognises that in order secure an acceptable level of social care services in the long-term future, additional sustainable funding must be identified. However, we are extremely concerned at proposals in the Green Paper to abolish Attendance Allowance (AA), and possibly Disability Living Allowance (DLA) for the over 65s, to help pay for care. We know how important these benefits are to maintaining the independence of people with Parkinson's, giving people the flexibility they need to meet the additional costs of their disability.

Forty one per cent of people with Parkinson's receive Attendance Allowance⁵ and this provides them with the flexibility to meet their care needs and live independently. The use of AA is not restricted in any way, making it in effect the perfect personal budget and one of the strongest elements of the existing care and support system. Local authority services could never provide the same level of choice and flexibility provided by AA. It is essential that these benefits are not lost in any new system. In the words of one of our supporters: *"Don't slay the chicken before a maintainable and adequate supply of eggs is established."*

"Attendance Allowance allows us to pay the heating bills and a cleaner to support us, the Government has no scheme that would support us in this." **Carer of person with Parkinson's**

"The person in receipt of AA has total flexibility as to how the money is spent and it gives the receiver discretion as to how to improve the quality of his/her life." **Carer of person with Parkinson's**

Respondents to the PDS survey report using the money in a variety of ways, from paying for personal care, getting help with housework and other tasks they can no longer manage, saving it towards adaptations to the home or a piece of equipment. In many cases the money is used for preventative interventions, such as the purchase of therapy services or aids and equipment. Abolishing AA would seem to contradict the government's commitment to increasingly personalised care.

"I need physiotherapy and massage, which I use AA to pay for, which keeps me at least mobile." **Person with Parkinson's**

"I can't do my garden any more, so I have to pay for help. I can't stand and iron any more, so I have to pay someone to do it. I can't wash my floors, I have to pay someone to do it. Without DLA I would be dirty, unkempt, and

living in a jungle. Is this what the government wants for the disabled and disadvantaged?" **Person with Parkinson's**

Attendance Allowance allows people to commission the care and support they need. The Green Paper proposals would formalise these informal, personalised support plans through local authorities, adding a costly layer of bureaucracy and depriving people of choice and control.

The Green Paper argues that Attendance Allowance is "intended for broadly the same purposes as social care" and that if it was abolished people's needs would be met by the improved system of social care envisaged in the National Care Service. However, AA and DLA are intended to help meet the costs of disability and many of the costs associated with Parkinson's would not be met by a National Care Service. Sixty three per cent of all respondents identified disability-related costs. These included 176 people with additional heating costs, 153 citing higher transport costs and over 100 people with high laundry and other cleaning costs due to incontinence. These are all costs that would not be met by a National Care Service.

AA was also used to fund personal care services, help with housework, gardening etc or saved up to pay for mobility aids or adaptations to the home. Other costs mentioned include: breakages (due to tremor), massage, increased insurance costs, the installation of grab-rails, help with odd jobs, cost of running a stairlift, careline alarm and special diet. The opportunity cost of the carer having to give up work was also highlighted in some responses.

"The £70 my husband now receives enables us to meet the necessary expenditure for petrol, heating, washing and toilet options." **Carer of person with Parkinson's**

AA is a godsend, also helps to pay for garden maintenance, etc. How am I supposed to pay for his food, transport, clothes, haircuts, toiletries etc without Attendance Allowance? **Carer of a person with Parkinson's**

"My husband has been recently diagnosed but already we are having additional costs, e.g. gardening, house maintenance, transport, jobs that we usually coped with ourselves now have to be done by outsiders without Parkinson's my whole life would be different and so would my costs of living." **Carer of person with Parkinson's**

Many respondents expressed concern that if Attendance Allowance is integrated into social care budgets the money will just disappear into local authority budgets and not reach those in need. Currently the numbers of disabled people exceed the number of people eligible for social care support. We believe that large numbers of people with Parkinson's could lose out if disability benefits were relocated to local authorities and their claims consequently subjected to a means-test. The introduction of means testing would also add an additional level of complexity to the system.

“A major concern in our county is the control of money provided for care and support services. Recently, funds for care of the elderly were devolved to local bodies and it has been estimated that up to eighty per cent of the money has been used in funding services not covered by the description ‘care of the elderly’.” **Mid Cornwall Branch, PDS**

The funding released by abolishing Attendance Allowance would appear to underpin all three of the funding models put forward by the government. However, there is a clear difference in the case for abolishing AA if all costs are met by the state (the Comprehensive model) than if only a third of costs are met by the state (the Partnership Model). Many disabled people would clearly lose out if they lost their Attendance Allowance but only received a small contribution to the cost of their care. This is reflected in feedback from our survey. Twenty six per cent would be happy for AA to be abolished if all care costs were met by the state,

The Green Paper includes a reassurance that anyone currently receiving disability benefits would receive an “equivalent level of support and protection.” However, this assurance includes no detail about what this protection would be. If people were offered services instead of the money they currently receive these may not be suitable to them. If the assurance is of an equivalent cash payment through direct payment or personal budgets then it is important that this guarantee is in real terms, not a fixed sum which would see people’s support lose value with inflation. Restrictions are often placed on how a personal budget or direct payment is used, and are therefore not as flexible as Attendance Allowance.

There are a number of other concerns with the proposal to abolish Attendance Allowance. AA and DLA are UK-wide benefits and the Green Paper does not include any detail on what the DWP anticipates would happen to the benefits in Wales, Scotland or Northern Ireland. This is a particular concern given the statement by the Secretary of State for Health that DLA for the under 65s will not be included in the reforms but DLA for the over 65s might be, as this raises a further query about how any transition will be managed if the systems are different in the four countries. Concern has also been expressed that disabled people in Wales would lose out from the reform, because the higher than average number of disabled people in Wales would not be reflected by the share of money allocated via the Barnett formula,⁶ with the same problem likely to arise in Scotland and Northern Ireland, which also have higher rates of disability than England.

The Green Paper also omits any detail of how passported benefits would be affected by the reform and support such as the Blue Badge Scheme, qualification for which is based on receipt of AA. Carer’s Allowance, the main benefit for carers’, requires the carer to be caring for a person in receipt of DLA or AA. The Green Paper includes no details as to what would happen to Carer’s Allowance if AA is abolished.

The vision of the National Care Service seeks to bring more people into the care and support system, however, there are currently far more people in receipt of disability benefits than there are in receipt of social care services. Unless the eligibility criteria are set a lower level of need many people who would be supported under the current benefits system would be likely to lose out. In recent years the majority of councils have raised the threshold for eligibility criteria in order to limit demand and expenditure on care services⁷. The Green Paper does not make clear what protection there will be, if any, to prevent the National Care Service raising the eligibility criteria as demand increases in light of an ageing population, and consequently excluding many disabled people from support.

Attendance Allowance is clear and transparent – if the claimant can demonstrate sufficient incapacity they will get benefit and be paid at the same rate wherever they live in the UK, avoiding the local inconsistencies that people experience in social care. Because it is non means tested, people know the exact amount they will qualify for if they meet criteria. These benefits must not be lost under any new care and support system.

Just five per cent of respondents to the PDS survey supported the proposal for Attendance Allowance to be subsumed into the funding for a National Care Service as described in the Green Paper. Seven per cent would be happy for a reduction in Attendance Allowance in light of improved support and twenty six per cent would be happy for AA to be abolished if all their disability-related costs were met. However, sixty two per cent were clear that they did not wish Attendance Allowance to be abolished under any circumstances. This strength of feeling cannot be ignored by the Secretary of State.

“The government is behaving like a mugger at a cashpoint. It sees old, frail and disabled people with cash in their hands and thinks ‘I’ll have some of that’. At least muggers only rob one person at a time.” **Person with Parkinson’s**

“AA is the only small bit of independence the disabled have.” **Carer of person with Parkinson’s**

6. Six principles for care and support

The six principles that underpin the envisaged National Care Service set out a welcome vision for care in the future, which if delivered, would address the problems people with Parkinson’s face in obtaining social care support. There was very strong support for all six principles, which demonstrates the need for reform to social care and shows that the Government is right to pursue a care service based on this vision.

The recent APPG for Parkinson’s disease Inquiry report⁸ highlighted inconsistencies in access to health and social care services across England, Wales and Northern Ireland. These problems included a shortage of information about how to access social care support, long waits for aids and adaptations to the home in many areas, poor joined up working between health and social care and a lack of respite and other support for carers. The

principles underpinning the Green Paper go some way towards addressing these problems and we eagerly await the detail in the White Paper.

All six principles were strongly supported by respondents to our survey, and reflect the views of the PDS and our members.

6.a. Prevention services

The PDS strongly supports the focus on preventative interventions, which should be central to any system of care and support.

There was considerable support for this principle, with seventy five per cent approval. Although this was the least popular of the principles it was still strongly supported, with a few people concerned that resources for prevention might direct money away from long-term conditions.

It is essential that early interventions in the management of long-term conditions are included in any prevention strategy. Low level interventions at an early stage can be of enormous benefit to people with Parkinson's and their carers and can help people with the condition live independently for as long as possible. These include access to therapy services, including physiotherapy and speech and language therapy, as well as the use of aids and adaptations.

The APPG for Parkinson's Disease Inquiry into Parkinson's services found that a preventative approach to a progressive condition like Parkinson's disease is cost-effective by avoiding unplanned admissions to hospital.⁹

The establishment of an independent body to develop best practice around preventative measures is to be welcomed, but its remit must include the management of long-term conditions.

6.b. National assessment

The PDS welcomes the proposal for a national assessment process, which will be an important step towards addressing the postcode lotteries that currently exist in social care provision.

The principle of national assessment was supported by ninety three per cent of respondents and would be an important step towards consistency of care across the country.

6.c. A joined up service

There is a clear need for a system that is joined up across health, social care and other local authority services, with ninety one per cent of respondents supporting this principle. We welcome the vision of a single assessment process and the commitment for regular review and reassessment of people's care.

Support needs to be as joined up as possible, so that the user experiences a unified system, with clear signposting between health and social care

services. As mentioned below, people identified GPs and other health services as the preferred source of information about social care.

Joined up working between health and social care has been a priority for many years, and further detail is needed as to how this would work in practice. In particular, people with Parkinson's want a seamless service that gives them the care they need.

6.d. Information and advice

We welcome the principle to improve the information and advice provided to people about the care and support available. The APPG for Parkinson's disease Inquiry Report¹⁰ highlighted the problems people with Parkinson's and their carers have accessing information about social care and navigating the social care system. Advocacy and advice are essential to support people to navigate the care system.

It is essential that the health service is closely engaged in provision of information about social care support. People with a long-term condition want a unified system, with signposting to support across health and social care boundaries. The PDS survey asked an additional question about how people would like to receive information about social care. By far the most common response was from their GP or healthcentre, with many other people choosing their Parkinson's Nurse Specialist and/or their consultant.

Ninety three per cent of respondents supported the principle of information and advice for all. Many respondents highlighted the PDS as an important source of information and it is important that the National Care Service works with local and national voluntary sector organisation to maximise access to information. For example, the PDS has a network of 330 branches, an extensive network of 120 Information and Support Workers covering all areas of the UK, as well as a national freephone helpline and a membership of 30,000 who receive the Parkinson magazine. The PDS also provides a wide range of publications and is seeking to be in the first wave of organisations accredited under the Information Standard.

6.e. Personalised care and support

The need for personalised care and support was widely welcomed by survey respondents, with ninety seven per cent supporting this principle. One of the problems people with Parkinson's report with the current system is that services are provided "to suit the council" and not built around the needs of the individual.

Though the principle of personalised care is welcomed, it is essential that people are supported to manage their personal budgets. During the 2008 consultation on the future of care some people expressed the concern that giving people control mustn't result in local authorities "washing their hands of you."

People need to be supported to manage a personalised service and the system must be built on best practice, with high quality information, advice, advocacy and brokerage.

The statement that “Under the new care and support system, once people are assessed they will get a personal budget rather than being told what services they should receive,” has implications for people lacking the capacity to manage a personal budget and would be a major culture change for service users to adjust to. The system must accommodate those that cannot, or do not wish to, have responsibility for coordinating their care and we would like to see this issue clarified within the White Paper. This is particularly relevant to those people with Parkinson’s related dementia.

6.f. Fair funding

There was strong agreement for the principle of fair funding, with ninety three per cent supporting this principle. However, as is apparent from disagreements about the preferred funding option, there is disagreement about what would constitute ‘fair’ funding.

Whatever funding option is preferred, it is essential that there is a substantial increase in the overall level of funding for the care and support system, not just to provide existing levels of care to meet demographic need, but to improve the overall level of care and support provided. It is therefore disappointing that the Department of Health hasn’t yet published the calculations that underpin the Green Paper. Without having these calculations in the public domain, informed engagement with stakeholders on this issue cannot take place.

7. Is there anything missing from the list of principles?

7a. Support for carers

Support for carers is central to the future delivery of care and support. Although this is recognised in the Green Paper, we would like to see support for carers embodied as one of the underlying principles of the National Care Service. This principle should clearly state that people should not be required to care if they do not wish, or are unable to do so.

The Green Paper lacks detail about how the National Care Service will support carers, and how it will build on and implement the National Carers Strategy¹¹. It is important that the White Paper includes these details.

Research by Carers UK has shown that to meet the demographic challenge of care in the future there will need to be 9 million family carers;¹² this is only achievable if carers are properly supported, with suitable and accessible respite and adequate financial support. We were therefore disappointed that the Green Paper did not outline any timetable or plan for a review of carers’ benefits. The problems with carers’ benefits are well documented¹³ and now that the Green Paper is published the government have no excuse for delaying reform.

Carers are not adequately supported under the existing care system. The PDS members' survey found that:

- over half of carers who need a break are not able to get one;
- nearly two thirds of carers were not aware of their right to a carer's assessment
- just over one in ten carers were receiving support from their local authority

Achieving a system where carers are supported both financially and by the care system generally is central to ensuring that any National Care Service is viable in the long term. The PDS urge the government to publish a timetable for their promised review of carers' benefits as a step towards this.

“What difference would a National Care Service make to spouses who would continue to care?” **Carer of person with Parkinson's**

7.b. Equipment and adaptations

Long waits for aids and equipment have been identified by people with Parkinson's as a major problem in many parts of the country. The Green Paper refers to the benefits of telecare but fails to highlight the preventative benefits of more traditional equipment, such as grab rails and other aids and equipment.

The PDS members' survey found that one in ten people thought their home was unsuitable, due to stairs or steps or because it needs adaptations. The recent Social Fund Commissioners' Annual Report¹⁴ found that social workers were referring people in need of equipment to the Social Fund, even when the council should be providing the equipment under the Chronically Sick and Disabled Persons Act. This failure to provide adaptations and equipment can force people into residential care prematurely and long waits for equipment restrict the quality of life for disabled people. It is essential that the White Paper clearly sets out how aids and equipment will be delivered within a National Care Service.

“I waited several months for a lightweight wheelchair, every time I inquired was told "it's not on the computer yet" or "the paperwork is not in the office.”
Person with Parkinson's

7.c. Responsible person – single point of contact

Several survey respondents identified the need for an identified contact that would be responsible for helping them to navigate the care and support system over the lifetime of their condition.

Although a commitment to universal information is welcome, people need help to navigate the health and care systems. Once identified, a person with a long-term condition should be brought under the umbrella of care services for the length of the condition. We would like to see the White Paper include a requirement for people with a long-term neurological condition to have a

named point of contact for advice and information and coordinating the individual's care plan¹⁵.

“Dedicated support workers assigned to each client to liaise on their behalf through dealings with social services, NHS and care home for a joined up service.” **Carer of person with Parkinson's**

“No one has any responsibility for me, which is fine as far as it goes, but it also means that no-one ensures that I have all the information/access to support that I might need.” **Person with Parkinson's**

8. Making the vision a reality

The PDS agrees that in order to deliver a National Care Service, services must be joined up, with greater choice and underpinned by quality and innovation. All of these changes were clearly supported by respondents to the PDS survey.

8.a. Joint working

Eighty five per cent of respondents supported a system of care and support that was more joined up and we welcome an approach that brings together all relevant services, including health, social care, housing and benefits. However, in addition to joint working, reform needs to address current confusion about the distinction between health and social care.

The Green Paper makes no reference to pooled budgets, but this would seem an important element in delivering joint care. In particular, preventative interventions funded by social care often make savings to the healthcare budget and preventative services need to be incentivised within the Care and Support system.

“Joined up services need joined up budgets.” **Carer of person with Parkinson's**

The Green Paper refers to the advantages of bringing together assessments for care and support and the claims process for disability benefits such as Attendance Allowance. The PDS accepts that a joint assessment process could be beneficial. People with Parkinson's talk about their frustration having to provide the same information to a range of professionals from different departments. There is potential to avoid unnecessary bureaucracy and allocate budgets more efficiently. However, although the PDS would support a move towards joint assessments we strongly reject this being used as an excuse for abolishing (some or all) disability benefits.

The National Care Service also needs to be transparent about which services will be funded by the NHS and which services are viewed as social care.

“My wife is so severely affected that she is fully funded by the NHS. This should continue under any future scheme and should be extended for those who have an acute illness like Parkinson’s that causes the need for social care.” **Carer of person with Parkinson’s**

8.b. A wider range of care and support services

Increasing the range of care and support services was supported by seventy two per cent of respondents to our survey.

However, whilst we welcome the move towards individual budgets and increasing individualisation, it is essential that people are supported to manage a personalised service, with high quality information, advice, advocacy and brokerage. There is also a danger that existing services will not be sustainable as more people use alternative service and further work is needed around service planning to limit the impact of this on service users.

8.c. Quality and innovation

Eighty six per cent of respondents agreed that the National Care Service will need to improve quality and innovation. Evidence about what works must include evidence about what works in supporting long-term conditions.

The PDS survey asked whether there was anything else that prevented the current social care system delivering the care they needed. The most common response was a need for better trained staff and better quality services. In particular, people identified the need for health and social care staff to have a better understanding of Parkinson’s and the impact of the condition on individuals and their families.

Many respondents also referred to the need for Parkinson’s Disease Nurse Specialists (PDNS), who can help people with Parkinson’s manage their condition. PDNSs have been shown to be cost effective, including reducing admissions to hospital.¹⁶

“Many people who have used respite services have been appalled by the lack of care and expertise.” **Person with Parkinson’s**

9. National or local decision making

Respondents to the PDS survey expressed very strong support for decisions about how much money should be spent to be made at national level, in order to address the current ‘postcode lottery’ in social care.

Just twelve per cent believed that decisions about how much money should be spent on care should be decided by local government, with twenty three per cent favouring national government and sixty five per cent favouring an independent national body.

“National assessment must identify need, but a standard level of care must take into account the geography and demography of the region.” **Mid Cornwall Branch, PDS**

10. Other issues

10.a. Funding for care of younger disabled people

The PDS is concerned that the Green Paper is overly focused on care and support of older people. Approximately half of people with Parkinson’s are diagnosed under the age of 65 and it is important that these people do not have to face a complicated transition to a new system when they reach retirement age.

It is important that reform to social care avoids creating a division between care for the over 65s and care for people of working age. A two-tier divided system will not work. Yet the section on the Comprehensive model states that this system would only work for people over retirement age. The PDS is extremely concerned that this could create a divided system that users would find difficult to navigate.

The introduction of means testing for disability benefits for those over retirement age would also create a disincentive for older disabled people to work. Many disabled people use their DLA to help with work-related costs. It is important that those older people who wish to and are able to work are supported to do so and the PDS is concerned that the introduction of a separate system for younger and older people would result in people being unable to carry forward the support that enables them to work, therefore forcing them to leave employment.

The National Care Service needs to establish greater joined-up working, not a new divide. The PDS strongly recommends that the government does not go down the route of establishing a separate system of care for older people.

“I had to change care managers at the age of 65 - mine was efficient and helpful, but now I have been forced to change, since when I have had nothing but problems. After almost one year my care plan is still not correct, the Carer's Assessment for my husband has been mislaid and the respite that we need has been ignored.” **Person with Parkinson’s**

10.b. Eligibility Criteria

The Green Paper also lacks details about how eligibility criteria would work under a National Care Service, i.e. what level of need would be met under the system. It is essential that eligibility is not set at too high a level. Currently too many people are unable to get the support they need because local authorities have restricted support to those in the highest levels of need.¹⁷

It is important that the eligibility criteria used in the National Care Service are fixed, in order to avoid the problem of criteria being raised in order to limit spending and to ensure clarity and transparency about the support that

people will receive. Over recent years seventy two percent of councils have restricted social care support to those with critical or substantial care needs.¹⁸ What assurance is there that the National Care Service will not be raised in a similar fashion in order to restrict spending as care needs increase in light of an ageing population.

The Green Paper states that under a National Care Service “everyone gets help with their high-level care costs”, which suggests that lower level needs would not be met. This would raise further concerns around the loss of Attendance Allowance and raises the concern that those with lower level needs will fail to get any support from the new system.

It is also unclear how the recent announcement by the Prime Minister of free personal care for those with high needs at home would fit into the National Care Service and whether the eligibility criteria for this would be the same.

11. Conclusion

The PDS welcomes the radical proposal of a National Care Service and supports the principles on which such a service would be based. However, we are opposed to the proposal of abolishing Attendance Allowance and other disability benefits as part of this reform.

Whatever system is used for funding care and support this must produce a substantial increase in overall funding in order to meet the needs of an ageing population and to improve the support provided. It is essential that the government publishes the full details of the calculations that underpin the Green Paper in order to enable informed debate. Unfortunately, these have not been available during the consultation period for the Green Paper, making it difficult to make an informed judgement on the options under consideration.

The White Paper must include detail on a number of issues not satisfactorily addressed within the Green Paper, including clarity about the eligibility criteria proposed for the National Care Service and how people of working age will be supported under the new system.

The principles that underpin the vision for the National Care Service must also address how carers will be supported and build on the National Carers Strategy, explain how aids and equipment will be delivered within a National Care Service and how preventative services will be targeted to support people to manage long-term conditions.

12. About the Parkinson’s Disease Society

The Parkinson’s Disease Society (PDS) was established in 1969 and now has 30,000 members and over 330 local branches and support groups throughout the UK. The Society provides support, advice and information to people with Parkinson's, their carers, families and friends, and information and professional development opportunities to health and social services professionals involved in their management and care.

This year, the Society is expected to spend £4 million on research into Parkinson's Disease. The Society also develops models of good practice in service provision, such as community support, and campaigns for changes that will improve the lives of people affected by Parkinson's.

Contact

If you would like further information about any of the issues raised in this response, please contact Dave Clark, Social Policy and Campaigns Officer, dclark@parkinsons.org.uk, 020 7963 9307.

References

- ¹ Prime Minister and Leader of the Labour Party Gordon Brown; speech to the Labour Party conference, 29 September 2009
- ² *Life with Parkinson's today – room for improvement*, Parkinson's Disease Society, 2008
- ³ *Please mind the gap: Parkinson's disease services today*, All Party Parliamentary Group for Parkinson's Disease, 2009
- ⁴ *Life with Parkinson's today*, op cit
- ⁵ *Life with Parkinson's today*, op cit
- ⁶ *Disabled people 'could lose out' under social care shake-up plan*, Martin Shipton, Weston Mail, 10 November 2009
- ⁷ *Cutting the Cake Fairly: Review of Eligibility Criteria*, Commission for Social Care Inspection, 2008
- ⁸ *Please mind the gap: Parkinson's disease services today*, op cit
- ⁹ *Please mind the gap: Parkinson's disease services today*, op cit
- ¹⁰ *Please mind the gap: Parkinson's disease services today*, op cit
- ¹¹ *Carers at the heart of 21st century families and communities: a caring system on your side, a life of your own*, Department of Health, 2008
- ¹² *It Could be You... ? The Chances of Becoming a carer*, Carers UK 2001
- ¹³ See for example *Valuing and Supporting Carers*, Work and Pensions Select Committee, House of Commons, 2008
- ¹⁴ Social Fund Commissioners Annual Report to Parliament, 2009
- ¹⁵ based on the Evidence Based Markers for Quality Requirement 1 of the National Service Framework for Long-term neurological conditions, Department of Health, 2005.
- ¹⁶ *Commissioning Parkinson's services: The clinical and financial value of Parkinson's Disease Nurse Specialists*, the Parkinson's Disease Society, 2007
- ¹⁷ *Cutting the Cake Fairly*, op cit
- ¹⁸ *Cutting the Cake Fairly*, op cit